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Caring for people with dementia: positive aspects, self-compassion and coping

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This thesis is submitted in partial fulfilment of the requirements for the
degree of Doctorate in Clinical Psychology

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Contents

Title Page	I
Contents	II
List of tables and figures	IX
List of abbreviations	X
List of appendices	XII
Acknowledgements	XIV
Declaration	XV
Summary	XVI
 Chapter 1: The positive aspects of caregiving in dementia: A critical review of the qualitative literature	
1.0 Abstract	2
1.1 Introduction	3
1.1.1 Caregiving context	3
1.1.2 Caregiver burden	3
1.1.3 Positive aspects of caregiving in dementia	4
1.1.4 Conceptualisations of positive aspects of caregiving	5
1.1.5 Methodological issues	6

1.1.6 Rationale for the current review	7
1.1.7 Aims	7
1.2 Method	8
1.2.1 Search strategy	8
1.2.1.1 Database search	8
1.2.1.2 Manual search	9
1.2.2 Selection criteria	9
1.2.2.1 Inclusion criteria	9
1.2.2.2 Exclusion criteria	9
1.2.3 Search results	10
1.2.4 Assessment of quality	11
1.2.4.1 Quality checklist	11
1.2.4.2 Results of quality appraisal	11
1.2.5 Analysis	13
1.3 Results	14
1.3.1 Study findings	14
1.3.1.1 Aim 1: How have positive aspects of caregiving in dementia been conceptualised in the qualitative literature?	23

1.3.1.1.1 Job satisfaction	23
1.3.1.1.2 Emotional rewards	24
1.3.1.1.3 Personal growth	24
1.3.1.1.4 Competence and mastery	25
1.3.1.1.5 Faith and spiritual growth	26
1.3.1.1.6 Relationship gains	27
1.3.1.1.7 Sense of duty	28
1.3.1.1.8 Reciprocity	28
1.3.1.1.9 Summary	29
1.3.1.2 Aim 2: How do caregivers of people with dementia perceive the process of positive caregiving?	30
1.3.1.2.1 Acceptance	30
1.3.1.2.2 Choosing a positive caregiving attitude	31
1.3.1.2.3 Commitment to relationship	32
1.3.1.2.4 Creating opportunities	32
1.3.1.2.5 Drawing strength from faith/past challenges/others	33
1.3.1.2.6 Summary	33
1.4 Discussion	34

1.4.1 Summary of the critical appraisal of studies in the review	37
1.4.2 Research implications	38
1.4.3 Clinical implications	40
1.4.4 Limitations	41
1.5 Conclusion	42
1.6 References	44

Chapter 2: An exploration of self-compassion, coping and carer burden in carers of people with dementia

2.0 Abstract	55
2.1 Introduction	57
2.1.1 Dementia context	57
2.1.2 Carer burden	57
2.1.3 Stress-process model	58
2.1.3 Coping strategies	59
2.1.4.1 Conceptualisation of coping strategies	59
2.1.4.2 Carers and coping styles	60
2.1.4.2.1 Dysfunctional coping	60
2.1.4.2.2 Problem-focused coping	61

2.1.4.2.3 Emotion-focused coping	61
2.1.4.3 Summary	62
2.1.5 Self-compassion	62
2.1.5.1 Conceptualisation of self-compassion	62
2.1.5.2 Empirical findings	63
2.1.5.3 Compassionate mind-set	63
2.1.5.4 self-compassion and coping	63
2.1.5.5 Summary	64
2.1.6 Rationale for current study	64
2.1.7 Aims and hypotheses	65
2.2 Methodology	65
2.2.1 Design	65
2.2.2 Participants	65
2.2.2.1 Sample size calculation	65
2.2.2.2 Participant description	65
2.2.3 Materials	66
2.2.3.1 Demographic information	66
2.2.3.2 Self-compassion	67

2.2.3.3 Coping strategies	67
2.2.3.4 Carer burden	68
2.2.4 Procedure	68
2.2.4.1 Ethics	68
2.2.4.2 Recruitment	69
2.2.4 Analysis	70
2.3 Results	71
2.3.1 Descriptive statistics	71
2.3.2 Correlation analysis	73
2.3.3 Mediation analysis	74
2.3.4 Post-hoc analysis	75
2.4 Discussion	76
2.4.1 Limitations	78
2.4.2 Clinical implications	79
2.4.3 Research implications	80
2.5 Conclusion	81
2.6 References	82

Chapter 3: Reflections on research methods and their meaning to participants and clinicians in healthcare settings

3.1 Introduction	90
3.2 My experience of choosing methods	90
3.3 Representing participant in research	93
3.4 Conduction and utilising research in healthcare settings	96
3.4.1 The influence of peers	97
3.4.2 The influence of the wider research context	98
3.4.3 The influence of health settings	99
3.4.4 Reflective practice	102
3.5 Conclusion	103
3.6 References	105

List of Tables

Table 1.1	Characteristics of studies reviewed	15
Table 2.1	Means and standard deviations of study variables	72
Table 2.2	Pearson's correlations of study variables	73

List of Figures

Figure 1.1	Study selection procedure	10
Figure 2.1	Stress-process model of stress in caregivers	59
Figure 2.2	Tests of mediations between self-compassion and carer burden	75

List of Abbreviations

ACT	Acceptance and Commitment Therapy
APA	American Psychological Association
BPS	British Psychological Society
CINAHL	Cumulative Index to Nursing and Allied Health Literature
COPE	Coping Orientations to Problems Experienced
DoH	Department of Health
HDA	Harmful Dysfunction Analysis
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
PAC	Positive Aspects of Caregiving
PwD	Person with Dementia
QR	Quality Rating
RCT	Randomised Control Trial
SCS-SF	Self-compassion Scale – Short Form
SPSS	Statistical Package for Social Sciences
UK	United Kingdom
USA	United States of America

ZBI

Zarit Burden Interview

List of Appendices

A	Author instructions for <i>Dementia</i>	107
B	Quality rating checklist	109
C	Author instructions for <i>Aging and Mental Health</i>	110
D	Participant demographic questionnaire	113
E	Self-compassion Scale – Short Form	116
F	Brief Coping Orientations to Problems Experienced scale	118
G	Zarit Burden Interview: Short Form	120
H	Confirmation of Coventry University ethical approval	122
I	Confirmation of local NHS Research Ethics Committee approval	123
J	Updated confirmation of local NHS Research Ethics Committee approval	125
K	Confirmation of Coventry and Warwickshire Partnership Trust Research and Development team ethical approval	127
L	Letter confirming the approval of the study by the Alzheimer’s society	129
M	Letter to potential participants from the Rugby Carers Course	130
N	Participant information sheet (NHS participants)	132

O	Participant information sheet (Non-NHS participants)	137
P	Consent Form	142
Q	Recruitment slip	143
R	Debrief sheet	144
S	Author instructions for <i>Reflective Practice</i>	146

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Declaration

This thesis has not been submitted for any other degree or to any other institution and is a record of original work carried out by me. The thesis was conducted under the academic and clinical supervision of Dr Tom Patterson (Clinical Psychologist, Coventry University) and Jane Muers (Clinical Psychologist). The original idea for this work was my own and followed discussions with the supervisors named above. The statistical analysis was conducted with the support of Ian Hume (Research Tutor, Coventry University). The named supervisors also read drafts of the chapters. Apart from the collaborations stated, all the material presented in this thesis is my own work.

Summary

This thesis explores the experiences of informal carers of people with dementia. Undertaking a caregiving role can have a wide range of implications for the carer from negative outcomes such as increased physical and psychological stress to positive experiences such as a sense of pride or mastery in the role. Through further exploration of these differing experiences, this thesis informs understanding of the caregiving role and suggests new directions for carer support and research.

The first paper is a critical review of the qualitative research exploring the positive aspects of caregiving in dementia. After database and manual searches were conducted, fourteen studies met the inclusion criteria and were reviewed. Carers across the studies consistently described a variety of positive aspects of caregiving. They also highlighted a number of factors that were important in supporting their positive caregiving experiences. Clinical implications relating to the inclusion of positive aspects in the holistic assessment and support of caregivers are discussed.

The second paper reports on a quantitative study that explored the relationship between self-compassion, dysfunctional and emotion-focused coping strategies and carer burden. Survey data was collected from 73 informal caregivers of people with dementia. Carers with higher levels of self-compassion reported lower levels of carer burden. The use of less dysfunctional coping strategies was found to mediate this relationship. Emotion-focused coping strategies were not found to be a mediator. Clinically, compassion-based interventions represent a potentially useful intervention for carers.

The final paper reflects on the differing contributions of qualitative and quantitative methodologies to research in psychology. The impact of the different methods on participants is considered along with the challenges to conducting diverse research in clinical settings. The scientist-practitioner nature of clinical psychologist role is noted as key in both respectfully representing participants and valuing the use of varied, clinically relevant research.

Overall Word Count: 16,703

Chapter 1: Literature Review

The positive aspects of caregiving in dementia: A critical review of the qualitative literature

Written in preparation for submission to *Dementia* (See appendix A for author instructions)

Overall chapter word count (excluding tables, figures and references): 7774

1.0 Abstract

Positive aspects of caregiving in dementia have been identified as important in understanding the experiences of carers, yet the research base lacks clear definitions of key concepts. Qualitative research explores carers' experiences of positive aspects of caregiving in rich detail which lends itself to supporting theory development. The aim of the present review was to critically evaluate the empirical findings of qualitative studies that have explored positive aspects of caregiving in dementia. A systematic search of the literature revealed 14 studies that met this aim. Carers described multiple positive dimensions of caregiving and identified several factors that were important in supporting their positive caregiving experience. The present review evidences a solid base of understanding of the positive aspects of caregiving in dementia from which concepts and theories can be further developed. Clinical and research implications are discussed.

Keywords: *Carers, dementia, positive aspects, qualitative*

1.1 Introduction

1.1.1 Caregiving context

In the context of a growing elderly population, dementia has been identified as an international priority (Department of Health (DoH), 2013). It is estimated that around 35.6 million people worldwide currently have dementia and this figure is set to double every 20 years reaching 115.4 million by 2050 (Alzheimer's Disease International, 2009). The majority of care and support for people with dementia is provided by family members, friends or neighbours (Knapp & Prince, 2007; Tremont, 2011). With the global cost of dementia in 2010 reaching 400 billion pounds, these informal carers of people with dementia have been recognised as an increasingly valuable resource (Wimo et al., 2010).

1.1.2 Caregiver burden

Over recent decades, a large volume of research has explored the negative impact of caregiving on informal carers (Etters, Goodall & Harrison, 2008). Studies indicate that caring can place a significant level of burden on caregivers resulting in poorer physical and psychological wellbeing (Bell, Araki & Neumann, 2001; Gallagher-Thompson & Powers, 1997). This in turn can affect the care they provide, sometimes leading to premature institutionalisation of the person with dementia (PwD) (Bédard, Pedlar, Martin, Malott & Stones, 2000) or even elder abuse (Wolf, 1998).

It has also been recognised that caring for a PwD can be more stressful than caring for a physically frail older adult (Schulz, O'Brien, Bookwala & Fleissner, 1995).

Carers have to contend with the challenging behaviours and distressing changes to personality that dementia can cause. Furthermore, the progressive nature of the illness means that over time, the caregiver is faced not only with increased care demands but also the gradual loss of the person they once knew (Clipp & George, 1993).

1.1.3 Positive aspects of caregiving in dementia

In comparison to caregiver burden research, there is a relative paucity of literature examining the positive aspects of caregiving (PAC). The research that has been conducted demonstrates that many carers cope well with the challenges they face and experience caregiving as a rewarding and satisfying experience (Cohen, Colantonio & Vernich, 2002; Farran, Keane-Hagerty, Salloway, Kupferer & Wilken, 1991).

Carers who report higher levels of PAC report lower levels of depression and anxiety as well as fewer feelings of being affected by the behaviour of the PwD (Mausbach et al., 2006; Pinquart & Sorensen, 2004). Additionally, the ability to find meaning in and derive gratification from the caregiving experience is associated with increased morale and a feeling of being more able to manage (Hirschfield, 1983). Importantly, those who reported higher satisfaction with caring were also less likely to institutionalise the PwD (Roff et al., 2004). Therefore, gaining an understanding of the factors that predict a more positive caregiving experience is important and could contribute to the development of interventions to support carers who are struggling (Rapp & Chao, 2000).

1.1.4 Conceptualisations of positive aspects of caregiving

The main body of research has attempted to integrate PAC into the same stress-coping model used to understand negative aspects of caregiving (Pearlin, Mullan, Semple & Skaff, 1990; Roff et al., 2004). However, other research has found that positive and negative aspects of caregiving are not opposite ends of the same continuum. Correlations between the two tend to be modest at most (Kinney & Stephens, 1989; Rapp & Chao, 2000) and predictors of positive and negative aspects are often not the same, with far fewer predictors of positive aspects being identified (Kramer, 1997b; Pinquart & Sorensen, 2004). Therefore PAC appear to be a separate dimension of the caregiving experience.

Studies that have considered this broader interpretation have conceptualised PAC in a number of different ways. Some studies have looked at overall positive appraisal of, or satisfactions with the caregiving experience (Lawton et al., 1989) whereas others have considered discrete daily events that trigger positive outcomes in carers (Kinney & Stephens, 1989). Further studies have focused on positive aspects in terms of impacts upon the carers themselves on variables such as their self-esteem or mastery (Semiatin & O'Connor, 2012), while others have investigated the enrichment or rewards generated by the dynamic reciprocity of the caregiving relationship (Cartwright, Archbold, Stewart & Limandri, 1994). These differing concepts may all play a role in the caregiving process but further work is needed, if they are to be integrated into a coherent framework.

1.1.5 Methodological Issues

One reason for the lack of clarity within this body of research is the reliance on quantitative methodologies to explore and understand what is ultimately a subjective experience (Bryman, 2008). Quantitative methods are based on a positivist perspective which views the world as a formation of measurable and observable facts. Caregiving research within this paradigm has attempted to identify specific processes that underpin positive and negative caregiver outcomes (Pinquart & Sorenson, 2004). However, identifying the details of these processes requires clear definitions of the concepts involved, something that has not yet been achieved within the PAC research base leading to conflicting results (Kramer, 1997a).

Furthermore, in attempting to identify processes which can be generalised across caregiving situations many of the nuances of the caregiving experience are lost and as such these quantitative approaches have been criticised for ‘...constraining the capacity of health care workers to fully understand the caregiving experience...’ (Butcher et al., 2001, pp 34-35).

In contrast, qualitative methods are based on an interpretative perspective which views reality as socially constructed and constantly changing. Qualitative research seeks to understand experiences by discovering and reconstructing processes from an insider viewpoint (Creswell, 2005). They offer an opportunity to gain insight into caregiving experiences and the meanings carers attribute to their role. These insights can be of immense clinical value and can also support the process of defining clear concepts and the development of theories (Hasselkus, 1998).

1.1.6 Rationale for the current review

In growing recognition of the value of qualitative research, a number of qualitative studies have investigated PAC in dementia. These studies are likely to shed new light on the area through allowing a detailed exploration of the experiences of distinct groups of carers and are therefore worthy of review.

Two previous reviews of PAC have been conducted in previous years (Carbonneau, Caron & Desrosiers, 2010; Kramer, 1997a). Both of these reviewed studies involving carers of people with a variety of mental and physical difficulties. As has been noted, caring for someone with dementia presents a unique caregiving situation and therefore warrants a separate review.

1.1.7 Aims

The primary aim of the present review is to critically evaluate the empirical findings of qualitative studies that have explored PAC in dementia. Within this, particular attention will be paid to:

- How PAC in dementia have been conceptualised within the qualitative literature.
- How carers perceive the process of positive caregiving.
- Exploring the qualitative differences between the experiences of different groups of carers (e.g. spouses vs children, husbands vs wives).

1.2 Method

1.2.1 Search strategy

1.2.1.1 Database search

A systematic literature search for relevant studies was performed using the following bibliographic databases: PsychINFO, Web of Science, Cumulative Index of Nursing and Allied Health Literature (CINAHL) and Scopus. The following search terms were used: care* AND Alzheimer's OR dementia AND 'positive aspects' OR 'positive experiences' OR 'positive perceptions' OR reward OR gain OR 'satisfaction with care*' OR 'care* satisfaction' OR benefit OR uplift OR meaning OR enjoyment OR pleasure AND qualitative OR 'grounded theory' OR phenomenological OR narrative OR ethnographic. These are consistent with terms used by Kramer (1997a) but extended to capture qualitative methodologies. The term 'carer' or 'caregiver' refers to those who provide support to someone with dementia, without receiving payment, including partners, spouses, adult children, friends or neighbours. No date limit was put on the search.

The titles and abstracts of the references generated were screened to assess their relevance. References that did not focus on the experiences of caregivers of a PwD or were clearly quantitative were discarded. This was kept deliberately broad to maximise the chance of detecting relevant studies as it has been identified that qualitative articles can have misleading titles or abstracts (Emslie, 2005). The references that focused on this area were located and assessed for inclusion in this literature review in line with the inclusion and exclusion criteria (section 1.2.2).

1.2.1.2 Manual search

The articles included in the present review were used as the basis for the manual search to identify additional references. The reference lists were searched and where possible, articles that had cited them were traced. As above, titles and abstracts were screened to assess relevance and those that focused on dementia caregiver experience were located and assessed for inclusion according to the inclusion/exclusion criteria.

1.2.2 Selection criteria

1.2.2.1 Inclusion criteria

The inclusion criteria were as follows:

- Studies in which at least one of the primary aims was to investigate PAC in dementia using a qualitative methodology.
- Participants were informal caregivers as opposed to voluntary or paid carers of people with dementia.
- Studies published in English.

1.2.2.2 Exclusion criteria

The exclusion criteria were as follows

- Quantitative studies with no qualitative data.
- Personal accounts of caring for someone with dementia with no analysis.
- Studies using discourse analysis.

- Studies in which it was not possible to separate carer data from data gathered from the PwD.
- Studies in which it was not possible to separate data from carers of people with dementia from carers of people with other physical or mental health difficulties.
- Studies that were not peer reviewed.

1.2.3 Search results

Following the selection procedure, 14 studies were included in the present review.

The study selection process is described in figure 1.1.

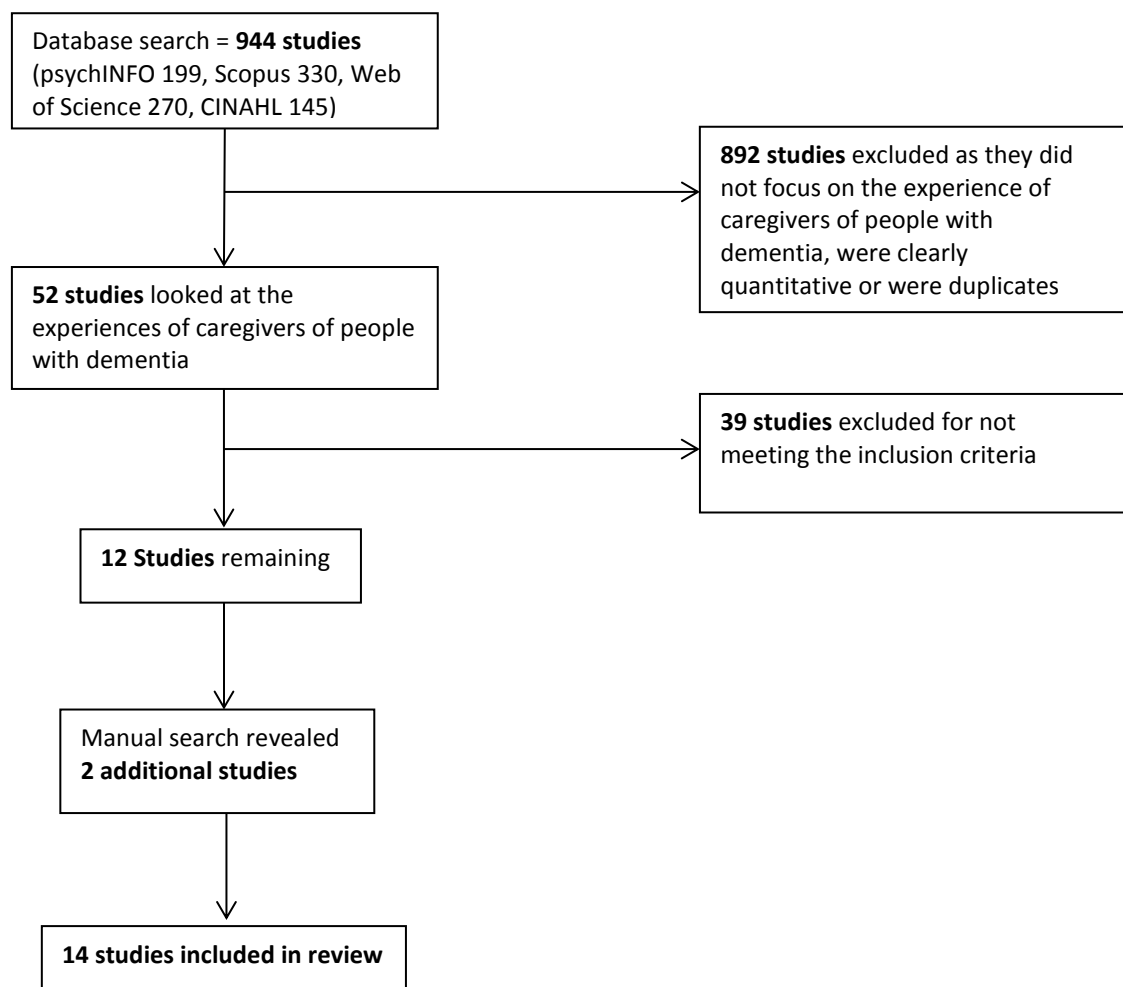


Figure 1.1 Study selection procedure.

1.2.4 Assessment of quality

1.2.4.1 Quality checklist

Following the systematic search, the 14 selected studies were appraised using a quality rating checklist (See Appendix B). Despite debate about the usefulness and feasibility of quality ratings in systematic reviews of qualitative literature, they can prove useful in guiding the critical evaluation of studies. There have been a number of attempts to develop structured approaches (e.g. Mays & Pope, 2000; Popay, Rogers & Williams, 1998; Walsh & Downe, 2006). The present review adopted a rating scale utilised by Greenwood, MacKenzie, Cloud and Wilson (2009) in their review of the qualitative literature on caring for someone following a stroke. Using this scale enables the present review to be comparable to others in the caregiving literature. Studies are scored from 0-11, with higher scores indicating the presence of more quality indicators. Due to the concerns regarding quality ratings, scores were not used to exclude studies, but instead were used to highlight strengths and limitations of the papers reviewed.

1.2.4.2 Results of quality appraisal

The studies scored between 7 and 11 on the quality rating checklist. These scores were similar to those reported by Greenwood et al. (2009) and demonstrate that despite some variability, a number of quality criteria were consistently met across the studies. For example, all but two studies (Duggleby, Williams, Wright & Bollinger, 2009; Netto, Jenny & Philip, 2000) demonstrated the use of more than

one researcher in the analysis and all but one (Netto et al., 2009) included a broad range of participants including cases of participants who did not experience PAC.

However, the assessment process highlighted a number of factors impacting on the quality of studies. Firstly, the majority of the studies reported on qualitative data collected as part of larger, mixed-method studies. In some cases, opportunity or convenience sampling was used to collect the large volumes of data required for the quantitative aspects of the studies as opposed to purposive sampling preferred in qualitative methodologies (Farran, et al., 1991; Murray, Schneider, Banerjee & Mann, 1999; Narayan, Lewis, Tornatore, Hepburn & Corcoran-Perry, 2001).

Purposive sampling is used in qualitative studies to target heterogeneity within a target sample of participants, thus enabling as broad a range of perspectives on the studied phenomenon to be captured as possible. Opportunity sampling may result in a varied sample; however, it is also possible that participants may share characteristics thus limiting the range of caregiver experiences available for analysis in these studies.

Furthermore, those studies that formed a part of a larger piece of research tended not to report as much detail of the data collection method, particularly in terms of who collected the data, their training and potential influence they may have had on the process (Butcher & Buckwalter, 2002; Farran et al., 1991; Jansson, Almberg, Grafström, & Winblad, 1998; Jervis, Boland & Fickenscher 2010; Peacock et al., 2010; Ribeiro & Paúl, 2008; Shim, Barroso, Gilliss & Davis, 2013). Even in cases where interviewer information was provided, in all but one study - Netto et al., 2009 - it was not the author of the study that carried out the interviews. As a result,

important qualitative nuances that develop in the dynamic between participant and interviewer may have been missed, which could affect the quality of the results presented in these studies.

With regard to analysis, the majority of studies made a good attempt to describe the techniques used to analyse the qualitative data. However, what was lacking in terms of quality was appropriate justification and theoretical underpinning for the methods chosen. The theoretical underpinning of the method enables the reader to understand the lens through which the data was analysed and therefore adds transparency to the findings. Some studies described using a range of 'common qualitative techniques' (Farran et al., 1991, p. 485) or reported engaging in different levels of coding with no theoretical basis (Narayan et al., 2001). Further studies utilised techniques from a particular theoretical position, most commonly grounded theory, but did not follow through with this approach to develop a theory grounded in the data (Jervis et al., 2010; Murray et al., 1999; Netto et al., 2009; Ribeiro & Paúl, 2008).

1.2.5 Analysis

Formal systematic review or meta-analysis is not considered appropriate when reviewing findings from qualitative studies (Barbour, 2003). The analysis in the present review employed techniques initially described by Britten and colleagues (Britten et al., 2002; Campbell et al., 2003) and adapted by Emslie (2005). Each paper was read to identify the main concepts of the study, study setting and participants. These details were compared systematically to detect common and recurring concepts. From this, similarities and differences in scope and findings

were established. Only findings relevant to the aims of the present review are presented here.

1.3 Results

1.3.1 Study findings

General study characteristics are displayed in table 1.1. It is noteworthy that none of the studies included in the present review were conducted in the UK. This may limit the utility of the conclusions of the present review for this population. It is possible that PAC occur in UK caregiving populations but have not been explored explicitly. Therefore, it could be important to investigate this further.

Study findings will be presented in terms of themes relating to the aims of the present review. The first aim sought to explore how PAC have been conceptualised within the qualitative literature. The findings of eight of the studies reviewed primarily met this aim. The second aim was to investigate how caregivers perceive the process of positive caregiving. The findings of six of the reviewed studies met this aim, although there was some overlap. Within these two sections, particular attention will be paid to the experiences of individual groups of carers (spouses vs adult children vs other relatives, husbands vs wives, sons vs daughters) where possible, thus meeting the third aim of the present review.

Table 1.1 Characteristics of the studies reviewed.

Author, date, country of origin and quality rating (QR)	Sample size, strategy description and recruitment location	Aims and topics covered	Data Collection (timing, location, interviewer etc.) and data analysis.	Participant details: gender, age, ethnicity, length of time caring and relationship to person with dementia	Key Findings
Butcher, H. and Buckwalter, K. (2002). United states of America (USA). Secondary analysis of data collected as part of a larger study. Quality Rating (QR) 8.	1. Paradigm case taken from a larger study. Original utilised opportunity sampling. Original study recruited through responses to radio adverts, newspaper notices and word-of-mouth in 7 communities in Arizona, Iowa, Indiana and Minnesota.	<i>Aims:</i> To develop a better understanding of how caregivers find meaning and joy in caring for a person with dementia. <i>Topics covered:</i> Carers asked to describe what caregiving was like in the context of caring for a family member with Alzheimer's disease living at home.	One unstructured interview conducted at the carer's home. Interviewer information not provided. Heidegger's hermeneutic phenomenological analysis.	1 female, Rose. 72 years. White. Caring for 13 years. Spouse.	3 themes Identified for how Rose transformed exasperations into blessings: <i>Living in cherished memories</i> involves finding joy in recalling and telling stories of enjoyable times she and her husband experienced together. In times of change, memories of past events take on meaning and inform the present. <i>Creating a 'happy' life by living life intensely.</i> From a Heideggerian perspective, a happy life takes shape only in the strong will and intense desire for it (Keisel, 1993). In this case, Rose creates opportunities for her and her husband to do meaningful activities together. Through this she creates a world in which her husband is 'happy and comfortable'. <i>Counting one's blessings.</i> Rose focuses on the positives in life, such as having good friends and that her husband still loves her and through this is able to find meaning in life. This focus is seen as a personal choice and in turn empowers her to take on further challenges.
Donovan, M. and Corcoran, M. (2010). USA. Secondary analysis	15. Sample was a subset of original data. Carers' qualitative data were selected	<i>Aims:</i> To explore how uplifted carers think about and conduct care. <i>Topics covered:</i>	Three 90 minute semi-structured interviews conducted over a 6 week period. Interviewers were	9 female, 6 male. Mean age 67.8 years. SD 11.8 years. 14 white, 1 other. Mean length of caring	Two main themes were identified in relation to how uplifted carers think about and carry out their caregiving activities: <i>Engaging in positive caregiver behaviours</i> encompassed practical adjustments such as simplifying routines, taking care of themselves, utilising the support of faith or religious

of data collected as part of a larger study. QR 11.	if they scored above the median on Caregiving Uplifts Scale. Purposive Sampling. Recruitment location not identified.	Caregiver's beliefs, meanings and actions related to caregiving.	trained occupational therapists. Constant comparative analysis.	5.4 years. All spouses.	communities and maintaining communication with their spouse. Caregivers described engaging in these behaviours to benefit both themselves and the care recipient. <i>Making adjustments in attitudes</i> involved practicing a positive attitude to caregiving. This included focusing on the positives, using humour and maintaining a commitment to the marriage and the relationship.
Duggleby, W., Williams, A., Wright, K. and Bollinger, S. (2009). Canada. QR 10.	17. Purposive and Theoretical sampling. Recruited through a home care coordinator.	<i>Aims:</i> To explore the experiences of hope from the perspective of family members caring for a person with dementia, specifically the processes of hope. <i>Topics covered:</i> Carers' interpretation of hope, what gives them hope, what changes it and how can others help them to have hope.	One 45-60 minute semi-structured interview conducted at the carers' home. (6 participants interviewed twice to clarify issues). Interviews conducted by research assistant. Grounded theory.	14 female, 3 male. 48-84 years, mean 65 years. All white. Length of caring 2-11 years, mean 5.5 years. 8 wives, 2 husbands, 5 daughters, 1 son, 1 friend.	The main concern of the participants was <i>fading hope</i> . Hope was fluid in nature and waxed and waned in relation to how the person they were caring for was doing each day. The basic social process that emerged was <i>renewing everyday hope</i> . Hope was described as the possibility of a positive future within a focus of living day by day. Participants described renewing everyday hope through <i>coming to terms</i> with their situation, <i>finding the positives</i> and <i>seeing possibilities</i> .
Farran, C., Keane-Hagerty, E., Salloway, S., Kupferer, S. and Wilken, C. (1991). USA. Data collected as part of a larger mixed methods	94. Opportunity sampling. Recruited from Alzheimer's disease centres, Alzheimer's association, adult day care programs,	<i>Aims:</i> To use an existential framework to explore how carers might grow and find meaning from their caregiving experience. <i>Topics covered:</i> Carers were asked to describe their current life	One 2 hour semi-structured interview at the caregiver's home. Interviewer information not reported. Type of analysis not identified other than	Gender information not given. 30-78 years. Mean 61.4 years. 81% white, 17% black, 2% other. Length of time caring not reported. 34% wives, 32%	Four major themes were identified: Loss and powerlessness, values choices and provisional and ultimate meaning, caregiving resources and responsibilities of caregiving. Only the first two were discussed and only the latter was relevant to this review. <i>Values, choices, provisional and ultimate meaning:</i> This was comprised of subthemes relating to making personal choices, valuing positive aspects, searching for provisional meaning and searching for ultimate meaning.

study. QR 8.	professional referrals and public service announcements in Chicago.	situation, any difficulties in caring, any pleasant aspects of caring, the changes they most regret, what gives them hope, what they need to maintain their caregiving role and the good things in life.	'common qualitative techniques'.	husbands, 24% daughters, 3% sons and 6% other family.	These themes support existential assumptions about finding meaning that people create meaning by making choices, that values provide basis for meaning and that provisional and ultimate meaning exist.
Jansson, W., Almberg, B., Grafstrom, M and Winblad, B. (1998). Sweden. Data collected as part of a larger mixed methods study. QR 8.	17. Purposive sampling Recruitment location not identified.	<i>Aims:</i> To explore the experiences of daughters caring for parents with dementia. <i>Topics covered:</i> Present feelings concerning caregiving, positive aspects of caregiving and motivations for caregiving.	One 90 minute semi-structured interview conducted at the Stockholm Gerontology Research Centre. Interviewer information not reported. Content analysis.	17 female. 41-66 years, mean 56 years. Ethnicity not reported. Length of time caring not reported. 15 daughters, 2 nieces (nieces described relationships with aunts as mother-daughter).	11 of the daughters identified positive aspects of caring. These related to two broad themes: <i>satisfaction</i> and <i>experience</i> . In addition, the daughters described their motivations to care. These were divided into three broad themes: <i>affection</i> , <i>reciprocity</i> and <i>duty</i> .
Jervis, L., Boland, M. and Fickenscher, A. (2010). USA. Data collected as	19. Purposive sampling. Carers were identified by elders recruited at senior nutrition sites, who were taking part in the	<i>Aims:</i> To explore caregiving among American Indians from the Northern Plains. <i>Topics covered:</i> Family lives, exchanges of assistance between the	One semi-structured ethnographic interview. Interviewer information not provided. Modified grounded	14 female, 5 male. Mean age not reported. 88.5% under 60 years. All American Indian. 81.3% caring for more than 3 years; 56.3%	The majority of participants described low levels of burden and high levels of reward. The rewards were linked to cultural attitudes of respect towards elders and caregiving, collective care provision, strong reciprocal relationships with the elders, enjoyment of elders company and relatively low levels of care provision. Caregiving appeared to be a more complex process than

part of a larger mixed methods study. QR 9.	larger study.	caregiver and the elder, problems helping the elder and both the difficult and positive aspects of caregiving.	theory approach.	caring for more than 10 years; 15.8% caring for 11 months or less. 8 children, 5 spouses, 4 grandchildren and 2 siblings.	simply a unidirectional provision of assistance from caregiver to elder and the positive experiences highlight the importance of elders in the American Indian community.
Murray, J., Schneider, J., Banerjee, S. and Mann, A. (1999) Europe. Secondary analysis of data from a larger study. QR 7.	280 (20 per country). Type of sampling not identified. Recruitment location not identified.	<i>Aims:</i> To explore whether there are differences in the rewards and stresses experienced by carers who live in countries with statutory rights to support and those who are bound by duty to care. <i>Topics covered:</i> Main difficulties in coping with dementia, rewards of caring, perceived social reactions to the person with dementia and subjective appraisals of support.	One semi-structured interview conducted 12-36 months post-diagnosis. Location of interview not reported. Interviewers were professionals experienced in dementia care and research. Content analysis and grounded theory.	162 female, 118 male. Mean age 71 years. Ethnicity not reported. Length of time caring not reported. All co-resident spouses.	18% of carers reported gaining no satisfaction from caring. The rest identified some rewards. The motivations expressed for these positive attitudes included: reciprocity for past care and affection; the desire for continued companionship; 'job satisfaction'; a perceived unique ability to look after their partner; and the fulfilment of a sense of duty. No differences were found in the positive experiences reported across countries or between husbands and wives.
Narayan, S., Lewis, M., Tornatore, J., Hepburn, K. and Corcoran-Perry,	43. Opportunity sampling. Recruited from	<i>Aims:</i> To explore how caregivers experience positive aspects of caring, caregiver	One semi-structured interview conducted at the carers' home. Interviewers were	37 female, 6 male. 50-88 years, mean 77 years. All white.	33% of carers explicitly mentioned positive feelings or advantages or opportunities present in their caregiving experience. Themes identified included <i>strengthening relationship, new</i>

S. (2001). USA. Data collected as part of a larger mixed methods study. QR 9.	support groups, physicians, HMOs, day care centres and other agencies.	competence, relational deprivation, role captivity and loss of self. <i>Topics covered:</i> What life is like as a caregiver and what life lessons they have learned through caring for a spouse with dementia.	research assistants trained in the interview process. Type of analysis not identified.	Length of time caring < 6 years. All spouses.	<i>learning and satisfaction in doing a good job.</i> 58% of carers expressed a mixture of positive and negative experiences. These were characterised by feelings of loss tempering the positive gains identified.
Netto, N., Goh, J. and Yap, P. (2009). Singapore. QR 10.	12. Purposive and theoretical sampling. Recruited from 3 dementia follow up clinics.	<i>Aims:</i> To investigate the gains experienced by family caregivers of persons with dementia. <i>Topics covered:</i> Areas of gain or growth experienced, personal changes, changes in the relationship with the person with dementia, positive feelings and experiences related to caring and any changes to their personal philosophy or outlook.	One semi-structured interview. Location of the interview not identified. Interviewer was the main researcher. Grounded theory approach.	10 female, 2 male. 32-72 years, mean 50 years. 11 Chinese, 1 Indian. Length of time caring not reported. 8 daughters, 2 sons and 1 spouse.	3 main themes of related to caregiver gains were reported: <i>Personal growth:</i> Included becoming more patient and understanding, stronger and resilient, self-aware, knowledgeable and better at problem solving. <i>Gains in relationships:</i> Included developing a closer relationship with the care recipient, becoming closer as a family and developing improved interactions with older people. <i>Higher level gains:</i> Included a positive change in philosophy, spiritual growth and altruism.
Peacock, S., Forbes, D., Markle-Reid, M., Hawranik, P., Morgan, D.,	39. Purposive sampling. Recruited through home care	<i>Aims:</i> To describe the positive aspects of caregiving identified by family carers of people	6 focus groups (N=36) and 3 personal interviews. Focus groups	32 female, 7 male. 17 carers <60 years, 5 carers 60-69 years, 9 carers 70-79	Using a strengths-based perspective as a guide, 5 themes emerged from the data: 1. An opportunity to give back. 2. Personal growth along the journey.

<p>Jansen, L., Leipert, B. and Henderson, S. (2010). Canada. Secondary analysis of data collected as part of a larger study. QR 10.</p>	<p>programs, support groups and away day programs in the Halton region of Ontario, Manitoba and Saskatchewan.</p>	<p>with dementia. <i>Topics covered:</i> Positive and challenging aspects of caregiving, experiences of accessing and using services.</p>	<p>conducted at the location of support groups and interviews were conducted in a location chosen by the participant. Interviewer information not provided.</p> <p>Interpretative descriptive qualitative analysis.</p>	<p>years, 8 carers >80 years. Ethnicity not reported. Length of time caring not reported. 22 spouses, 13 children, 1 niece and 3 other.</p>	<p>3. Discovery of inner strengths by connecting with others. 4. A sense of competence in the role. 5. An opportunity for a closer relationship and commitment to the care receiver.</p>
<p>Ribeiro, O. and Paúl, C. (2008) Portugal. QR 11.</p>	<p>53 (27 caring for a wife with dementia, 26 caring for a wife with a physical impairment). Purposive sampling. Recruited from psychogeriatric services, social and health agencies and day centres.</p>	<p><i>Aims:</i> To explore the positives aspects of care experienced by older men caring for their chronically ill wives. <i>Topics covered:</i> Meanings and difficulties or caring role, thoughts about stress and coping and reflections on gender issues.</p>	<p>2 hour unstructured interview at the participants care home or a support centre. Interviewer information not reported.</p> <p>Grounded theory approach.</p>	<p>All male. 67-88 years, mean 77.9 years. Ethnicity not reported. Mean length of time caring 4.7 years. All husbands.</p>	<p>32 of the 53 carers reported feelings of gain and these were all associated with <i>commitment</i> and <i>duty</i>. Two main themes were identified: <i>Satisfaction</i> included marital relationship, care work and self-protectiveness. <i>Perceived social honour</i> included social recognition and wife's appreciation. Of the 32, 18 were carers of wives with dementia, suggesting this group are more likely to experience gain. There were no significant differences between husbands caring for wives with dementia as opposed to physical health problems other than the former were more likely to report satisfaction with providing assurance of the care recipient's wellbeing. The main difference between husbands who experienced gains and those who did not were that the former reported</p>

					a more positive relationship prior to the onset of illness.
Sanders, S. (2005). USA. QR 10.	85. Opportunity sampling. Recruited through an East Coast chapter of the Alzheimer's association.	<i>Aims:</i> To explore how caregivers of individuals with Alzheimer's disease characterise both the strain and gain they experience through caring. <i>Topics covered:</i> Main caregiving problem and what changes they have experienced within themselves as part of their caregiving experience.	Participants were asked to respond to a series of open ended questions incorporated into a written survey. Grounded theory approach.	59 female, 26 male. 28-89 years, mean 60 years. 46 White, 26 African-American, 9 Hispanic, 4 Asian. Mean length of time caring 4 years. 40 daughters, 18 wives, 17 husbands, 10 sons.	69 of the carers reported experiencing some gain and these feelings tended to be associated with personal feelings about themselves and their ability to perform a task that they originally did not think they were able to. 3 main themes emerged: 1. Spiritual growth and increased faith 2. Personal growth 3. Feelings of mastery and accomplishments Husbands were the most likely group to report feelings of gain overall. Notably, wives were more likely to experience feelings of increased spirituality than daughters.
Shim, B., Barroso, J. and Davis, L. (2012). USA. Secondary analysis of data collected as part of a larger study. QR 10.	21. Opportunity sampling. Recruited from memory clinics, geriatric clinics, private medical practices, home care agencies and support groups.	<i>Aims:</i> To gain an understanding of the factors that differentiate the carers who experience positive caregiving experiences from those who do not, with a focus on relationship aspects and to explore the meaning that carers find in caring. <i>Topics covered:</i> Areas of	Three semi-structured interviews conducted (baseline, 6 months and 12 months). Location of data collection not stated. Interviewers were female social or nurses trained to use the research project interview data. Manifest and latent	16 female, 5 male. 47-91 years, mean 71years. 17 white, 2 black and 2 other. Mean length of time caring 6 years. All spouses.	Three groups of carers identified (negative, ambivalent and positive). The negative group described both their past and present relationship in negative terms. They could not identify positive experiences, did not make other-focused comments but instead focused on their own (unmet) needs. The ambivalent group described their past relationship as mainly positive but were more conflicted in their current relationship. They described satisfactions in caring relating to the positive quality of the past relationship and in doing a 'good job' but also described feeling overwhelmed and uncertain and struggled to accept the changes occurring in their spouse.

		caring that are most difficult and areas of caring that stand out as having been positive.	content analysis and thematic analysis.		The positive group described both their past and present relationship in positive terms. They described multiple positives and satisfactions in terms of cherishing what remained and 'giving back' love received during the marriage. They appeared able to accept the situation and as such had a sense of peace and were able to find meaning in their caregiving experience.
Shim, B., Barroso, J., Gilliss, C. and Davis, L. (2013). USA. QR 10.	11. Opportunity sample. Recruited using leaflets and word-of-mouth from support groups, geriatric clinics, adult day centres, senior centres, churches and events and via email within rural counties in a south-eastern state in the United States.	<i>Aims:</i> To explore how spousal caregivers find personal meaning in their caregiving experience. <i>Topics covered:</i> The meaning caregivers find in caring, how they think they find this meaning and how this meaning has changed or affected the caregiving experience.	One semi-structured interview conducted at a location chosen by the caregiver. Interviewer information not provided. Thematic analysis.	6 female, 5 male. 63-81 years. 10 white, 1 African American. 1-14 years of caring. All spouses.	Themes were grouped according to the 3 research questions. <i>Meaning in caregiving:</i> Meaning stemmed from the spouse and from the caregiving itself. Meaning derived from the spouse was linked to keeping them at home, upholding marriage vows and returning care received during marriage. Meaning derived from caregiving was linked to personal growth. <i>How caregivers found meaning:</i> Caregivers described meaning emerging from their situation rather than actively seeking it. Strategies that enabled carers to find meaning were accepting the situation, deciding to care, choosing a positive attitude, focusing on the blessings and actively seeking resources. Common characteristics that also helped carers find meaning included altruistic values, discipline and determination to live their values, faith, love and the ability to derive strength from past challenges. <i>Changes from finding meaning:</i> Changes described by carers included a sense of peacefulness, a deeper understanding of self and deeper connection with their spouse.

1.3.1.1 Aim 1: How have positive aspects of caregiving in dementia been conceptualised in the qualitative literature?

1.3.1.1.1 Job satisfaction

A sense of satisfaction with carrying out caregiving duties well was reported by carers in most studies. Feelings of satisfaction were particularly associated with doing a good job (Jervis et al., 2010), keeping the PwD safe (Peacock et al., 2010) or making them as comfortable as possible (Murray et al., 1999).

However, there also appeared to be a difference between carers in the quality of the satisfaction experienced. Studies reported that some carers approached their caregiving roles in a practical and unemotional way, deriving satisfaction from simply 'doing their best' (Murray et al., 1999, p665). Other studies suggested that some carers found a deeper satisfaction. Ribeiro and Paúl (2008) described carers experiencing a sense of pride in carrying out care-related activities to a high standard and reported that carers found a new sense of purpose in their caring role. Shim, Barroso and Davis (2012) further demonstrated that carers who were ambivalent about caring tended to find satisfaction in discrete activities, such as visiting friends; whereas positive carers reported a more overarching sense of pride and satisfaction in their role.

Studies that explored this further suggested that previous quality of relationship may be important in understanding these different experiences. Carers who derived less satisfaction from caring spoke about their previous relationship with their spouse or parent in negative terms and reported caring out of obligation, without

enjoyment (Jansson et al., 1998; Ribeiro & Paúl, 2008; Shim et al., 2012). These carers were committed to their role, but did not express the same pride and satisfaction in the role as carers who reported having a positive prior relationship with their spouse or parent.

1.3.1.1.2 Emotional rewards

As well as job satisfaction, carers across the studies spoke of emotional rewards gained through caring. These were often related to feeling appreciated or successful and such comments were particularly poignant when they came from the PwD themselves (Jansson et al., 1998; Jervis et al. 2010; Netto et al., 2009; Ribeiro & Paúl, 2008). In addition, some adult child carers specifically described enjoying the company of elderly people (Jervis et al., 2010; Netto et al., 2009). For husbands in particular, there was an emotional reward in the perceived social honour of being a man caring for his wife (Ribeiro & Paúl, 2008).

1.3.1.1.3 Personal growth

Many of the studies reported that caregivers described having 'grown intrinsically' as a result of their role (Netto et al., 2009, p. 250). Particular areas of growth included increased patience (Peacock et al., 2010), self-respect (Jansson et al., 1998) and being more self-aware (Sanders, 2005). Some studies referred to a sense of peace that seemed to be present in those carers who spoke of personal growth (Peacock et al., 2010; Sanders, 2005). This growth appears to be separate from personal development achieved through learning new skills (see 1.3.1.1.4).

Male carers (husbands and sons) were more likely than female carers to describe personal growth in terms of becoming more humble (Netto et al., 2009; Ribeiro & Paúl, 2008). Furthermore, personal growth may be more salient to adult child carers and husbands than to wives who care. In Sanders' (2005) study, husbands and daughters were more likely to report personal growth, whereas wives were more likely to report spiritual growth. In addition, studies that included predominantly adult child carers in their sample found personal growth to be the most consistently reported gain (Jansson et al., 1998; Netto et al., 2009), whereas studies focusing on spousal carers tended to report relationship gains more consistently.

1.3.1.1.4 Competence and mastery

Alongside personal growth, studies reported that carers described gaining a sense of competency or mastery in the role as a positive aspect of caregiving (Netto et al., 2009; Narayan et al., 1999; Murray et al., 1999; Peacock et al., 2010; Ribeiro & Paúl, 2008; Sanders, 2005). They spoke of caregiving as providing an opportunity to learn new skills both in terms of caring specifically (Ribeiro & Paúl, 2008) and also transferable skills, such as problem-solving (Sanders, 2005). For many carers, the sense of competence went beyond simply mastering new skills to a feeling that they had achieved something they did not think they were capable of (Jansson et al., 1998; Sanders, 2005). Many spoke of wanting to share their skills and knowledge with others and some were even considering changing career to a caring profession (Peacock et al., 2010).

In particular, husbands reported increased confidence and self-worth as a result of learning new skills such as cooking or housework which had traditionally been the domain of their wives (Ribeiro & Paúl, 2008).

1.3.1.1.5 Faith and spiritual growth

Increased faith and spiritual growth was mentioned as a positive aspect across many of the studies, but was emphasised differently depending on the sample of carers. In some studies, spiritual growth was a strong and consistent theme among carers (e.g. Sanders, 2005). These studies tended to have taken place in the USA with caregivers identifying themselves as being of Christian faith. These carers described their faith as enabling them to take on the caring role and providing them with the strength to continue (Netto et al., 2009). This was particularly salient for wives caring for husbands (Sanders, 2005).

Other studies with more spiritually and religiously diverse samples recognised faith as a valuable source of support for some carers, but acknowledged that it did not apply to all (Peacock et al., 2010; Ribeiro & Paúl, 2008). Further studies described carers as experiencing a broader positive change in philosophy rather than specific spiritual growth (Netto et al., 2009). These carers spoke of placing less value on material goods and focusing more on relationships. Regardless of religious background, caregivers appeared to have gained a broader perspective on life and found their lives to have new meaning as a result of caring.

1.3.1.1.6 Relationship gains

The majority of studies referred to relationship gains as a positive outcome of caring. Spousal carers described gains relating to companionship and simply being in the company of their husband or wife, even if the other could no longer reciprocate (Ribeiro & Paúl, 2008). They also referred to the onset of dementia and the associated growing dependency as strengthening their relationship and bringing greater emotional closeness (Murray et al., 1999). Both husbands and wives explained that engaging in caring tasks increased the intimacy in the relationship (Peacock et al., 2010; Ribeiro & Paúl, 2008).

For adult child carers, relationship gains often came in the form of strengthening a relationship with a parent that had become distant as a result of everyday life (Jansson et al., 2008; Netto et al., 2009). They spoke of the onset of dementia as an opportunity to spend time with and really get to know their parent or grandparent (Jervis et al., 2010). In addition, these carers reported gains in the relationships with their own immediate family. They identified that caregiving encouraged them to appreciate those around them more (Netto et al., 2009; Jervis et al., 2010).

Only one study, Sanders (2005), did not comment on relationship gains amongst their findings. It is likely that this is because participants were asked particularly about the changes they had noticed in themselves as a result of their caregiving, leading to self-focused answers. Furthermore, they were asked to provide responses in written format, limiting the opportunity for any elaboration of responses.

1.3.1.1.7 Sense of duty

In many studies, spousal carers reported finding rewards in following through a sense of duty. They explained that there was an intrinsic reward in upholding their marital vows and expressed pride in being able to care for their lifelong spouse (Murray et al., 1999; Ribeiro & Paúl, 2008). Similarly to 'job satisfaction' (section 1.3.1.1.1), spouses with a prior positive relationship were more likely to report these feelings (Ribeiro & Paúl, 2009; Shim et al., 2012).

This intrinsic reward in fulfilling a sense of duty was reported less often by adult child caregivers. However, it featured in Jervis and colleagues (2010) study with American Indian caregivers. Both adult child and grandchild carers expressed pleasure in being able to uphold cultural values of caring for their elderly. They consistently commented that this commitment was diminishing within the community, but that they were proud to be following tradition.

1.3.1.1.8 Reciprocity

In addition to fulfilling a sense of duty, many studies reported that carers found satisfaction in the notion of reciprocity, or the opportunity to give back to their loved one (Jervis et al., 2010; Murray et al., 1999; Peacock et al., 2010; Ribeiro & Paúl, 2008). Carers spoke of wanting to repay the love and care they had received from their spouse or parent (Peacock et al., 2010; Jansson et al., 1998). It was noted across studies that husbands in particular were keen to pay back the love and care they had received whereas wives tended to view caring as a continuation of the relationship (Murray et al., 1999; Peacock et al., 2010; Ribeiro & Paúl, 2008).

In some cases this reciprocity was future focused, with adult child carers acknowledging the influence of the knowledge that they would be old one day and may be in need of care (Jervis et al., 2010). Some even highlighted that through caring for their parent, they were able to demonstrate to their children what may be expected of them in the future (Peacock et al., 2010).

However, similarly to satisfaction, reciprocity was more likely to be cited as a reward by carers who had a previous positive relationship with their parent or spouse (Ribeiro & Paúl, 2008). Those daughters who had previously had a difficult relationship with their mothers reported caring ‘...in the absence of either affection or reciprocity’ (Jansson et al., 1998, p. 279).

1.3.1.1.9 Summary

The qualitative empirical literature reviewed here shows that caring for someone with dementia has many potential positive aspects. Some of these were derived from the caregiving itself such as job satisfaction, competence and mastery, and both personal and spiritual growth. The remainder related to the interpersonal dynamic between the carer and the care-recipient including relationship gains, satisfaction in reciprocity and from fulfilling a sense of duty. However, there appeared to be some overlap, for example emotional rewards resulted both from feeling successful within the caregiving role and feeling appreciated by the PwD. Furthermore, there also appeared to be an interaction between the two areas with prior relationship quality impacting upon the degree and type of satisfaction experienced.

The majority of PAC were experienced by all groups of carers reported on in these studies with some subtle differences. For example, personal growth appeared to be more salient for adult child carers, whereas spouses tended to focus on relationship-based PAC. Furthermore, husbands seemed to gain from the opportunity to give back the love and affection they had received from their wives and the perceived social honour of being a male carer whereas wives viewed caregiving as a continuation of the relationship. The relationship gains experienced by carers also varied between groups. Spouses spoke of ongoing companionship and increased intimacy with their spouse, whereas adult children described getting to know their parent. Adult children also reported relationship gains extending beyond the carer – care recipient dyad to their immediate family.

1.3.1.2 Aim 2: How do caregivers of people with dementia perceive the process of positive caregiving?

Studies reviewed in relation to the second aim utilised different methods to explore carers' perceptions of positive caregiving. Some took 'uplifted' carers and studied their thoughts on their caring role (Butcher & Buckwalter, 2001; Donovan & Corcoran, 2010), others asked carers how they find 'hope' or 'meaning' (Duggleby et al., 2009; Farran et al., 1991; Shim et al., 2013) and one compared negative, ambivalent and positive carers (Shim et al., 2012).

1.3.1.2.1 Acceptance

A key factor in experiencing caregiving as positive was acceptance of or coming to terms with the situation (Donovan & Corcoran, 2010; Duggleby et al., 2009; Shim et

al., 2012; 2013). Carers reported having to relinquish previous plans, focus on living day by day and accept the limitations of the PwD (Duggleby et al., 2009; Shim et al., 2013). Coming to terms with the situation was seen to involve gaining an understanding of what they were dealing with (Duggleby et al., 2009) and through this they could be compassionate and empathic towards the PwD (Shim et al., 2013).

1.3.1.2.2 Choosing a positive caregiving attitude

In addition to accepting the situation, carers across studies spoke of choosing the attitude they took towards their caring role. There was an acknowledgement that resentment could develop, but that they could choose whether or not this dominated their outlook (Farran et al., 1991; Shim et al., 2013). In particular, carers described making an active choice to look at the positives in the situation. Uplifted carers in Donovan and Corcoran's (2010) study spoke about 'practicing a positive attitude' (p. 592) by dwelling on positive thoughts and avoiding negative ones. In other studies carers described counting blessings (Butcher & Buckwalter, 2001), cherishing what remained (Shim et al., 2012) or choosing to use humour to make a positive situation out of a negative one (Donovan & Corcoran, 2010; Farran et al., 1991; Shim et al., 2013). By making this personal choice to focus on the positives, carers seemed to be empowered to continue to face the challenges of their role (Butcher & Buckwalter, 2001).

In terms of specific caregiving groups, Farran and colleagues (1991) noted that spouses were more likely to report actively making this choice than adult child carers. Few other studies looked at different groups of carers.

1.3.1.2.3 Commitment to relationship

Spousal carers across the studies described how commitment to their relationships enabled them to maintain positive attitudes towards caring (Donovan & Corcoran, 2010; Farran et al., 1991; Shim et al., 2013). They spoke of the love they still had for their partner and the love they received in return. This love helped them to put their partner first and be compassionate towards them at times of difficulty (Shim et al., 2013). The uplifted carers in Donovan and Corcoran's (2010) study described how maintaining their commitment to their spouse enabled them to maintain their stamina for caring.

Similarly to some of the PAC discussed above, carers who described their relationship prior to the onset of dementia in positive terms were more able to draw upon their commitment to their marriage to empower them to continue caring (Ribeiro & Paúl, 2008; Shim et al., 2012). Butcher and Buckwalter (2001) highlight the importance of cherished memories as part of this process. Being able to find joy in memories of the PwD prior to the onset of dementia can inform how carers view them in the present.

1.3.1.2.4 Creating opportunities

The majority of studies reported that carers created opportunities for the PwD to engage in meaningful activities. Carers suggested that if the PwD were happy and comfortable then they could be too (Butcher & Buckwalter, 2001). Furthermore, as with adopting a positive attitude, carers described this as an active choice. The

carers in Duggleby and colleagues (2009) study spoke of hope arising through setting goals with the PwD.

1.3.1.2.5 Drawing strength from faith/past challenges/others

Carers also described drawing strength from various sources in order to remain positive. Some spoke about drawing strength from faith (Duggleby et al., 2009), some from past challenges (Shim et al., 2013) and others from supportive friends, family or services (Donovan & Corcoran, 2010). Utilising these sources of strength enabled carers to maintain a balance in their lives and continue caring in the face of hardship. Of note, Sanders (2005) reported that carers who struggled to report gains in their caregiving experience were more likely to be caring in isolation.

1.3.1.2.6 Summary

Carers identified a number of salient factors that helped them to achieve and maintain the positive aspects within their caring roles. Acceptance appears key in enabling carers to take a positive attitude towards caring. This attitude does not necessarily come naturally, but instead requires caregivers to make a choice and to practice it. Furthermore, acceptance of the changes in the PwD and in the case of spousal carers, commitment to the relationship, allows carers to be compassionate and empathic towards the PwD at times of difficulty. These carers continue to involve the recipient of care in activities to maintain their self-worth, creating an environment in which the PwD is as happy and comfortable as possible. They are also able to draw strength from resources such as their faith or support networks.

There was less exploration of the experiences of different groups of carers in this aspect of the literature. One key difference noted by Farran et al. (1991) was that spousal carers were more likely to make an active choice to take a positive attitude towards their caring role than other carers. However, the literature on adult child caregivers was sparse and this factor is worthy of further exploration.

1.4 Discussion

The primary purpose of the present review was to critically evaluate the empirical findings of qualitative studies on the PAC in dementia. Specifically, the aims were to explore the contribution of qualitative research to the conceptualisations of PAC, carers' perceptions of the positive caregiving process and to gain an understanding of the experiences of different groups of carers.

Positive aspects for all groups of carers arose from two broad areas: those gained from the caring itself and those derived from the dynamic between the caregiver and the PwD. The former included satisfaction, emotional rewards, personal growth, competence and mastery and increased faith and spiritual growth while the latter encompassed relationship gains, satisfactions in reciprocity and fulfilling a sense of duty.

Studies that explored caregiver perceptions of the process of positive caring highlighted a number of significant factors that appear to contribute to this.

Primarily, the positive aspects described by carers did not simply appear, but were achieved through the choices and strategies adopted by the carers. In particular, acceptance of the situation and the on going implications of this appeared to be an

important step. This enabled carers to make a choice to view the situation with a positive attitude and be compassionate and empathic towards their loved one. Furthermore, choosing to commit to the relationship whilst drawing upon sources of strength and creating meaningful opportunities for the PwD to be happy and comfortable, appeared to empower carers to continue in their caregiving role. Using such adaptive strategies enabled carers to go beyond just coping with the situation, to growing and taking something positive from it.

The use of qualitative methodologies to explore in detail the experiences of participants has highlighted the multiple dimensions of PAC. Furthermore, by providing a platform for the voices of the caregivers, the qualitative studies reviewed here have demonstrated the importance of these experiences. These caregivers spoke with passion and emotion, describing how they had not just adapted to their circumstances but how they had been able to take something good from them and in some cases, be changed for the better by them. It is noteworthy that for some of the papers reviewed, the initial purpose of collecting the data was not to look for positive experiences, yet these were so prominent within the data that they prompted re-analysis and further articles to be written (Butcher & Buckwalter, 2001; Peacock et al., 2010).

A striking finding of the present review was the remarkable degree of consistency in the positive aspects reported by carers across the studies. Despite studies being conducted in a number of locations around the world, at different times and using different theoretical frameworks and methodologies, similar findings were reported throughout. Of particular note were the studies conducted by Farran et al. (1991)

and Duggbleby et al. (2009). The former adopted a deductive, theory-driven approach to explore how carers found meaning in their role, whereas the latter took an inductive grounded theory approach to investigating carers' experiences of hope. Despite these very different approaches they reached similar conclusions in terms of caregivers making personal choices to care and to take a positive attitude to caring, valuing these positive aspects and drawing on the support of those around them and their faith to maintain their caregiving role.

There were subtle differences in how PAC were experienced by different groups of carers. Adult child carers seemed to find personal growth a particularly salient outcome. Caregiving was identified as an opportunity to learn more about themselves and appeared to give them confidence in their ability to handle difficult situations in the future. In contrast, spousal carers, particularly wives, tended to place a higher value on gains based in the dynamic of their relationship and on spiritual growth. These differences support previous research (Ott, Sanders & Kelber, 2007) and may reflect the different times of life that these carers embark on their caregiving journey. Adult child carers tend to be younger and therefore may have had less opportunity for personal development than older spousal carers.

For husbands, both of these domains appeared to be salient. They were reported as gaining particularly from the opportunity to reciprocate the care they had received through the marriage and from the new sense of purpose gained from taking on the caregiving role. Wives, by contrast, viewed their caring role as an extension of their marital relationship. Furthermore, husbands reported benefitting from a perceived social honour of being a male carer. In terms of the gender perspective, this

supports previous research which has suggested that the social recognition associated with being a male carer is intrinsic to the positive caring experiences of husbands (Rose & Bruce, 1995). However, the findings of the present review suggest that this is not the only means by which male carers experience caregiving as positive and that other factors, such as gaining a new sense of purpose, are important and worthy of further investigation.

Notably, prior relationship quality appeared to be a significant factor in understanding the experience of PAC. Carers who described their prior relationship with the PwD in positive terms were more likely to report a deeper level of satisfaction in their role and appeared more able to draw satisfaction, pride and strength from the reciprocity of the relationship. This finding is in line with previous research which highlights that prior relationship quality may be an important factor that influences a number of aspects of the caregiving journey. For example, relationship quality has been shown to influence motivation to undertake a caregiving role, with carers who describe a positive prior relationship being more likely to be motivated by an intrinsic desire to maintain quality of life for the PwD rather than an extrinsic motivation based on obligation (Quinn, Clare & Woods, 2010). Furthermore, a recent review demonstrated that a positive prior relationship results in better outcomes for both the caregiver and PwD (Ablitt, Jones & Muers, 2009).

1.4.1 Summary of the critical appraisal of studies in the review

Overall, the studies in the present review scored relatively well on a quality framework checklist. However, those studies with lower scores tended to fall down

on aspects relating to data collection, reporting of methodology and analysis. In particular, the data in several studies was collected as part of larger mixed method studies and therefore not collected or reported with the necessary rigour. Whilst the process of analysis of the data was generally described well, studies often lacked an appropriate justification and theoretical underpinning for the methods chosen. Some studies drew techniques from particular methodologies and used them in isolation without rooting them in their theoretical framework. The theoretical frameworks of different qualitative methods are key to helping the reader understand the epistemological position of the researcher and how they view the data. Without this, those studies lack some transparency and the usefulness of their conclusions can be limited.

1.4.2 Research implications

The quantitative research base underlying PAC in dementia currently lacks clear definitions of key concepts which could hinder further progress in developing understanding in the area (Kramer, 1997a). The qualitative research reviewed here provides a rich and detailed insight into caregivers' experiences. Not only do the findings highlight the breadth and depth of the positive experiences of the carers, they also give insight into how these are achieved and the subtle differences between groups of carers. As such, the present review evidences the presence of a consistent and solid base of understanding from which concepts can be further defined and operationalised through quantitative studies.

The present review also demonstrates the flexibility of qualitative methods. For example, the papers by Donovan and Corcoran (2010) and Shim et al. (2012) took

qualitative data from specific groups of carers to examine their different experiences thus furthering understanding of how and why different carers experience PAC. This type of secondary analysis is not without critics (Hinds, Vogel & Clarke-Steffen, 1997); however these studies had quality ratings similar to or higher than those of original studies reviewed and therefore represent alternative and novel means of examining the experiences of participants which should be encouraged.

In terms of further research, the present review highlights the importance of separating out groups of carers in studies. Whilst there was some overlap in the positive experiences of husbands, wives and adult child caregivers, there were important subtle differences meaning that carers should not be considered a homogenous group. The majority of studies reviewed looked at spousal or mixed groups of carers and thus future work focusing specifically on adult child and other sub-groups of carers could be valuable.

In addition, further research is needed to explore whether or not the positive experiences identified by carers of people with dementia in the present review extend to carers of people with other physical or mental health difficulties. For example, a recent paper exploring the experiences of adult children caring for parents with either Alzheimer's disease or Parkinson's disease reported similar findings of enjoying time together, becoming closer and giving back care (Haberman, Hines & Davis, 2013). This suggests that the findings from the present review may be generalizable to other caregivers and this is worthy of further investigation.

1.4.3 Clinical implications

The present review supports previous findings that PAC are important to caregivers (Kramer, 1997a). It is therefore important to recognise this fact in order to facilitate the provision of a holistic approach to supporting family carers. Expanding the assessment of carers by health or social workers to include the positive aspects could be a useful first step, enabling support and validation to be provided to those who experience caregiving as rewarding. Furthermore, the absence of positive aspects could be seen as a risk factor when identifying carers who are struggling. However, it is also important that the presence of PAC is not exploited as a reason for not encouraging caregivers to access services from which they and the PwD could benefit.

The present review has also demonstrated that PAC do not simply occur for carers, but are dependent on their choices and strategies which suggests a potential opportunity for intervention. Notably, acceptance of the situation appears to be a key first step in being able to view caregiving as a positive experience. Interventions based on this such as Acceptance and Commitment Therapy (ACT; Hayes, Strosahl & Wilson, 2004) could be helpful to carers struggling at this point. ACT promotes a mindful acceptance of the present. Specifically, it acknowledges the struggles that people might experience but suggests that engaging with the difficult thoughts and feelings that arise from them may not be helpful. Instead, it encourages people to adopt a values-based approach to life through identifying what is truly important to oneself and setting goals accordingly. This seems consistent with the experiences of positive carers described in the studies reviewed. Initial pilot studies have

demonstrated positive outcomes and support this as a viable avenue for further investigation (Losada & Márquez-González, 2011).

Another key finding of the present review was the importance of relationship variables in how carers experience their caregiving role. Prior relationship quality appeared to be central in predicting positive experiences and many gains reported were relationship based. Therefore, including the PwD in work to support the carer may be beneficial. This could include supporting the carer and PwD to engage in meaningful activities together or encouraging them to share memories if appropriate (Donovan & Corcoran, 2010).

1.4.4 Limitations

Only studies published in English were included in the present review, potentially limiting the findings which could be discussed. In addition, the inclusion criteria limited studies to those which had a primary aim to explore PAC through a qualitative methodology. This meant that studies which discovered positive aspects serendipitously through other research questions were excluded, again limiting the findings which could be discussed.

The present review raises methodological questions regarding the critical review of qualitative studies. There is debate regarding quality ratings of qualitative studies and particularly whether to include all studies that meet inclusion criteria or to exclude studies based on quality. The present review decided on the former approach due to difficulties in deciding what constitutes good design and to minimise bias by excluding 'poor' studies. Furthermore, it could be argued that

another way to approach the present review with a focus on different groups of carers would be to use a meta-synthesis to synthesise and compare the results for different groups (spouses, adult child etc.). However, this would have been difficult with carers falling into more than one group (husbands vs wives, spouses vs adult child, sons vs daughters). The decision to conduct a critical review allowed these relationships to be explored more freely.

1.5 Conclusion

In light of the conflicting quantitative evidence base regarding the PAC in dementia, the present review aimed to critically evaluate the qualitative literature in this area. The findings highlight a consistent and thorough base of qualitative evidence describing the multiple dimensions of PAC experienced by carers as well the factors that caregivers identify as important in developing and maintaining a positive caregiving experience. In particular, the present review demonstrates that PAC do not just occur for carers but are at least partly the result of their choices and strategies. The use of qualitative methodologies allowed the subtleties within the experiences to be examined, especially in relation to the different groups of carers. The present review reinforces previous findings that carers should not be considered a homogeneous group and advocates for further research with specific sub-groups of carers such as adult children. Clinically, the findings presented support the inclusion of PAC in holistic carer assessments and also identify opportunities for intervention with carers, for example through the techniques used within ACT. Further research is needed to investigate whether the findings relating to PAC in the present review can be generalised to carers of people with

difficulties other than dementia, however, they do provide a solid base from which concepts and theories in this area can be developed.

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Chapter 2: Empirical Paper

An exploration of the relationship between self-compassion, coping strategies and carer burden in carers of people with dementia

Written in preparation for submission to *Aging and Mental Health* (see Appendix C for author instructions)

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2.0 Abstract

Objective: Caring for a person with dementia can be stressful and can result in negative physical and psychological consequences for carers, a phenomenon known as carer burden. Coping strategies have a mediating role in the impact of caregiving-related stress. Specifically, using emotion-focused strategies has been associated with lower levels of burden, whereas dysfunctional strategies have been related to increased burden. The concept of self-compassion (being kind to oneself when things go wrong) has been linked to positive outcomes. It also appears to buffer people from the effects of stress and has been associated with the coping strategies that are most advantageous to carers. However, as yet, no research has studied self-compassion in carers. Therefore, the aim of this study was to explore the relationship between self-compassion, coping strategies and carer burden in informal carers of people with dementia.

Method: Cross-sectional survey data was collected from 73 informal carers of people with dementia recruited from post-diagnostic support services and carer support groups.

Results: Self-compassion was found to be negatively related to carer burden and dysfunctional coping strategies and positively related to emotion-focused coping strategies. Dysfunctional strategies mediated the relationship between self-compassion and carer burden, whereas emotion-focused strategies did not.

Conclusion: Carers with higher levels of self-compassion report lower levels of carer burden and this is at least partly due to the use of less dysfunctional coping

strategies. Interventions based on developing self-compassion could represent a useful intervention for carers who are struggling.

Key Words: *Carers, carer burden, coping strategies, dementia, self-compassion*

2.1 Introduction

2.1.1 Dementia context

Dementia is a disorder that involves a global decline in intellectual functioning affecting memory, planning, judgement and self-care skills and also affects personality and behaviour (American Psychological Association (APA), 2000). There are a number of causes with the most common including Alzheimer's disease, vascular dementia, and Lewy Body disease. There are currently over 35.6 million people diagnosed with dementia worldwide and this figure is set to double every twenty years reaching 115.4 million by 2050 (Alzheimer's Disease International, 2009). The majority of these people are cared for by informal carers such as family members, friends or neighbours (Knapp & Prince, 2007).

2.1.2 Carer burden

Carers of a person with dementia have to cope with the cognitive decline and behavioural changes that accompany the condition, whilst also having to manage to loss of the relationship with the person as they used to be. It is therefore not surprising that research indicates that caring for a friend or relative with dementia can be stressful and detrimental to both the carers' physical and psychological wellbeing (Bell, Araki & Neumann, 2001; Gallagher-Thompson & Powers, 1997).

The concept of carer burden has received considerable attention in the literature. It is a complex construct with authors distinguishing between objective burden, the physical aspects of caregiving and subjective burden, the psychological consequences of being a carer (Zarit & Zarit, 1982). Furthermore, it is recognised

that caring also places a strain on caregivers' social and financial wellbeing (Zarit, Todd & Zarit, 1986). However, despite this association, not all carers appear to suffer in these ways and many cope well with their role (Kramer, 1997).

Understanding the processes that underpin these different reactions has therefore been a priority for researchers in this area.

2.1.3 Stress-process model

The most widely used paradigm for understanding how people cope with stress is the stress-process model (Lazarus & Folkman, 1984). This suggests that stressful events alone do not determine the intensity of the negative outcome. Instead, the impact of stress is mediated by the person's appraisal of the stressor and the coping resources they employ to manage it. This model has been extended specifically to understand the process of caregiver stress (see figure 2.1; Pearlin, Mullan, Semple & Skaff, 1990). The authors suggest that a number of domains make up this process and these interact on multiple levels forming a complex process that varies widely among caregivers.

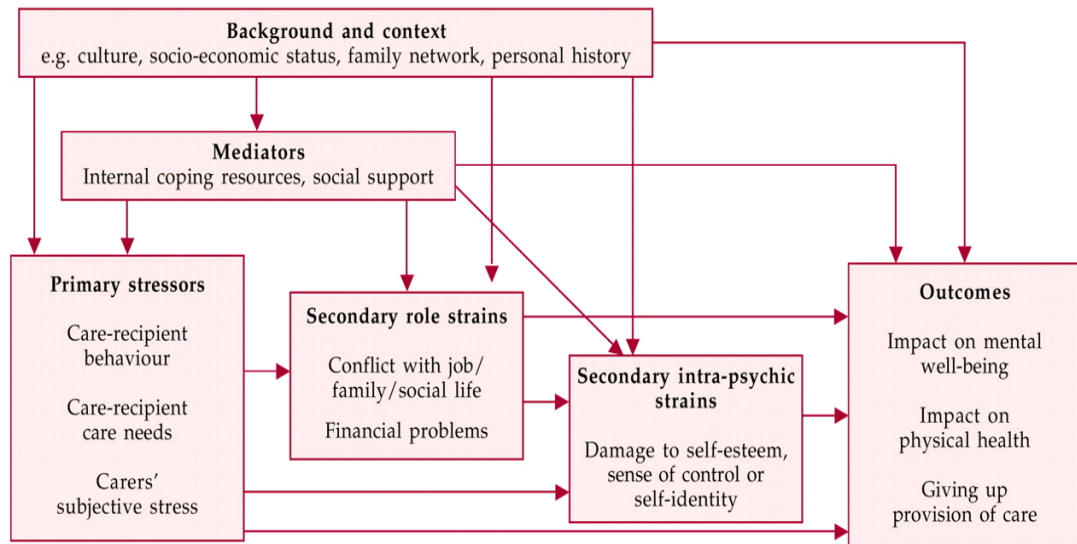


Figure 2.1. Stress–process model of stress in carers (adapted from Pearlin et al., 1990)

2.1.4 Coping strategies

2.1.4.1 Conceptualisation of coping strategies

Coping strategies are the means by which people manage stress (see figure 2.1).

There have been numerous attempts in the literature to define and organise different categories of coping strategies (for a review see Skinner, Edge, Altman & Sherwood, 2003). The most consistently used were initially proposed by Lazarus and Folkman (1984), as part of the stress-process model. Two broad categories of strategies were suggested: emotion-focused and problem-focused. Emotion-focused strategies refer to processes that serve to reduce the emotional distress associated with the stressor, for example through acceptance, positive restructuring or humour. Problem-focused strategies look to try to change the situation for the better. These include generating alternative solutions, planning and taking action to resolve or circumvent the stressor. Which strategy is beneficial depends on the nature and context of the stressor.

Research has also sought to identify distinct types of strategy that serve particular functions, whilst also aiming to distinguish between helpful and unhelpful coping (Carver, Scheier & Weintraub, 1989). Using evidence from Lazarus and Folkman's (1984) model as well as a model of behavioural self-regulation (Carver & Sheier, 1981), Carver and colleagues (1989), identified 14 distinct strategies which fall into three categories: emotion-focused strategies including acceptance, emotional support, humour, positive reframing and religion; problem-focused strategies, including active coping, instrumental support and planning and a third category, dysfunctional coping represented less helpful strategies. These include behavioural disengagement, denial, self-distraction, self-blame, substance use and emotional venting (Carver, 1997).

2.1.4.2 Carers and coping styles

2.1.4.2.1 Dysfunctional coping

In carers of people with dementia, dysfunctional coping strategies have been consistently linked to higher levels of depression (Kim, Knight & Longmire 2007; Li, Cooper, Bradley, Schulman & Livingston, 2011), anxiety (Cooper et al., 2010) and carer burden (Wright, Lund, Caserta & Pratt, 1991) as well as lower satisfaction with life (Sun, Kosberg, Kaufman & Leeper, 2010). Furthermore, the use of more dysfunctional strategies has been shown to mediate the relationship between stressors and depression, anxiety and burden in carers, both in cross-sectional (Mausbach et al., 2006) and longitudinal studies (Vedhara, Shanks, Wilcock & Lightman, 2001).

2.1.4.2.2 Problem-focused coping

The literature relating to problem-focused coping strategies presents a more mixed picture. Some research suggests that problem-focused strategies can be advantageous to carers of people with dementia (Kneebone & Martin, 2003); whereas other research indicates that they are unrelated to carer mental health (Li et al., 2011). It has been suggested that problem-focused strategies can help people feel more positive in the short term, but that these strategies do not reduce the demands of the caregiving role (Cooper, Katona, Orrell & Livingston, 2008). Furthermore, there is evidence to suggest that employing active, problem-solving strategies in response to negative life events that cannot be changed can be frustrating and detrimental to mental health (Bailly, Joulaim, Hervé & Alaphilippe, 2012).

2.1.4.2.3 Emotion-focused coping

Using more emotion-focused coping strategies, such as acceptance, has been linked to lower levels of depression and anxiety in carers of people with dementia (Kneebone & Martin, 2003; Li et al., 2010). It seems likely that many problems faced by carers of people with dementia are intractable, especially as length of time caring increases and therefore people need to adapt emotionally. Longitudinal research suggests that emotion-focused strategies buffer caregivers from developing higher anxiety and increased feelings of burden over time (Cooper Katona, Orrell et al., 2008; Vitaliano, Russo, Young & Terri, 1991).

2.1.4.3 Summary

The type of coping strategies used by caregivers appears to influence the impact of the stress of the role. In particular, emotion-focused strategies seem to buffer caregivers from the negative impact of stress whereas dysfunctional strategies leave carers more susceptible to it. Therefore, it seems appropriate to investigate factors that promote adaptive emotion-focused strategies and discourage dysfunctional coping in order to develop interventions that can promote wellbeing and reduce feelings of burden amongst carers of people with dementia. The present study aims to build on the literature by investigating the role of self-compassion in the caregiver stress process.

2.1.5 Self-compassion

2.1.5.1 Conceptualisation of self-compassion

At the heart of the concept of self-compassion is the idea of treating oneself kindly when things go wrong. In the same way that people can show compassion towards others in times of difficulty, those who are self-compassionate respond to their own problems with self-directed kindness as opposed to being self-critical and judgemental (Neff, 2003a).

Self-compassion has been conceptualised as having three components each of which has two parts, the presence of one and the negation of the other: (a) being kind to oneself as opposed to being self-critical; (b) accepting ones failings as part of being human rather than isolating oneself because of them and (c) being mindful

of one's thoughts and feelings as opposed to avoiding or over identifying with them (Neff, 2003).

2.1.5.2 Empirical findings

Current research indicates that those high in self-compassion tend to score highly on other measures of wellbeing. Self-compassion has been associated with higher life satisfaction and subjective wellbeing as well as lower anxiety and depression (Neely, Schallert, Mohammed, Roberts & Chen, 2009; Neff, 2004). These positive associations appear to continue across the lifespan with studies demonstrating that self-compassion can be a predictor of dimensions of positive ageing such as ego integrity and meaning in life (Philips & Fergusson, 2013).

2.1.5.3 Compassionate mind-set

Preliminary research findings also suggest that a compassionate mind-set can be developed (Adams & Leary, 2007). As such, clinical interventions aimed at increasing self-compassion have begun to emerge. Initial results suggest that these may be helpful in reducing symptoms of depression, anxiety and self-criticism as well as improving participants' ability to self-soothe (Gilbert & Proctor, 2007). This could represent a potentially useful intervention for carers.

2.1.5.4 Self-compassion and coping

Research has shown that people higher in self-compassion experience less anxiety when confronted with stressful events than people low in self-compassion, even when self-esteem is accounted for (Neff, Kirkpatrick & Rude, 2007). This suggests that self-compassion buffers people from the effects of stress and could be involved

in the coping process. A study that explored this further found that students who were higher in self-compassion responded more adaptively and resiliently in the face of a perceived academic failure. Notably, they were more likely to use emotion-focused strategies, such as acceptance or positive reinterpretation and were less likely to use dysfunctional avoidant strategies such as denial or mental disengagement (Neff, Hseih & Dejitterat, 2005). This suggests that one mechanism by which self-compassion may act is through influencing and adapting coping strategies.

2.1.5.5 Summary

Studies indicate that self-compassion is linked to positive outcomes across the lifespan and that inducing a compassionate mind-set appears to be a promising intervention for those experiencing psychological difficulties. Despite this encouraging evidence, there has been no research thus far looking at self-compassion in carers of people with dementia. However, research linking self-compassion and coping supports this as a viable avenue for investigation.

2.1.6 Rationale for current study

The evidence above suggests that an exploration of the relationship between self-compassion, coping and carer burden would inform understanding of the caregiver stress process. Not only does self-compassion demonstrate significant positive associations with indices of wellbeing, it also appears to be related to coping strategies that are most adaptive for caregivers. As a trait, low levels of self-compassion could signify vulnerability to carer burden and when induced, a

compassionate mind-set could represent a potential therapeutic intervention to improve carer quality of life.

2.1.7 Aims and hypotheses

The overall aim of the proposed study is therefore to explore the relationship between self-compassion, coping strategies and carer burden. In line with the rationale outlined above, four hypotheses are proposed:

- 1) Self-compassion will be negatively related to carer burden.
- 2) Self-compassion will be positively related to emotion-focused coping strategies.
- 3) Self-compassion will be negatively related to dysfunctional coping strategies.
- 4) The type of coping strategy used will mediate the relationship between self-compassion and carer burden.

2.2 Methodology

2.2.1 Design

A cross-sectional survey research design was used to explore participant's perceptions of self-compassion, coping strategies and carer burden.

2.2.2 Participants

2.2.2.1 Sample size calculation

Klein (1998) recommends that when using regression analysis, such as that used in mediation analysis, 20 participants per variable investigated should be sufficient to assess significance. The model under investigation has one predictor variable, two

possible mediators and one outcome variable. Therefore, according to this recommendation, a sample size of 80 was deemed sufficient.

2.2.2.2 Participant description

Participants were self-identified informal carers of a friend or relative with dementia. To be eligible for inclusion in the study, carers were to be over the age of 20 years and engaging in at least 5 hours of care related activities per week. Overall, 73 carers took part in the study. The majority were female (n=54) which is consistent with previous caregiver research. Ages ranged from 39-87 years (mean=67.21, SD=11.47). The majority of participants described their ethnicity as White British (94.5%) with the remainder identifying themselves as White Non-European (2.4%), other (1.4%) or did not want to say (1.4%). Over two-thirds of carers were spouses (69.9%) with the next biggest group being children (20.5%). The remainder were siblings (4.1%) or 'other' (5.5%) including daughters-in-law and friends.

2.2.3 Materials

2.2.3.1 Demographic information

Single items assessed age, gender, ethnicity, relationship to the care recipient, whether carers resided with the care recipient and highest level of education achieved (Appendix D).

2.2.3.2 Self-compassion

The 12-item Self-Compassion Scale – Short Form (SCS-SF; Raes, Pommier, Neff & Van Gucht, 2011; Appendix E) was used to assess self-compassion. Example items include ‘I try to be understanding and patient towards those aspects of my personality that I don’t like’ and ‘when something painful happens, I try to take a balanced view of the situation’. Responses are recorded on a 5 point Likert-type scale from 1=almost always to 5=almost never. Negative items are reversed scored and all items are summed to create an overall self-compassion score. The index has demonstrated good internal consistency ($\alpha=.86$) and shows a near perfect correlation for with the full scale ($r=.98$).

2.2.3.3 Coping strategies

Two subscales of the Brief COPE (Coping Orientations to Problems Experienced; Carver, 1997; Appendix F) were used. This self-report measure is a shortened version of the COPE index (Carver et al., 1989) which assesses 14 different coping strategies. These strategies can be averaged into 3 subscales: emotion-focused coping, problem-focused coping and dysfunctional coping (Coolidge, Segal, Hook & Stewart, 2000). Participants respond on a 4 point Likert-type scale from 1=I haven’t been doing this at all to 4=I’ve been doing this a lot. The present study is concerned with emotion-focused and dysfunctional strategies and therefore only these subscales were used. These have been investigated with carers of people with dementia and demonstrate good internal consistencies (Emotion-Focused $\alpha=.72$ and Dysfunctional $\alpha=.75$; Cooper, Katona & Livingston, 2008).

2.2.3.4 Carer burden

The Zarit Burden Interview: Short form (Bédard et al., 2001; Appendix G) was used to assess carer burden. The original Zarit Burden Interview (ZBI; Zarit, Orr & Zarit, 1985) is the most consistently used measure in the dementia caregiver literature. It considers the most common problem areas reported by caregivers including health, psychological wellbeing, finances, social life and relationship with the care recipient. Participants record how frequently they experience these issues on a 5 point Likert-type scale from 0=never to 4=nearly always. It demonstrates strong internal consistency with an α coefficient regularly in the .90s (McConaghy & Caltabiano, 2005; Zarit, Anthony & Boutsellis, 1987). The short form is a 12 item version which shows excellent correlations with the original ($r=.92-.97$, Bédard et al., 2001).

2.2.4 Procedure

2.2.4.1 Ethics

Ethical approval for the present study was granted by Coventry University Ethics Committee (Appendix H), the local Coventry NHS Research Ethics Committee (Appendices I and J) and the Coventry and Warwickshire Partnership Trust Research and Development team (Appendix K). This was deemed satisfactory for conducting research within the voluntary organisations approached: the Alzheimer's Society (Appendix L), Rugby Dementia Support and the Alcester Carers Group. The study protocol also adhered to the British Psychological Society's (BPS) Code of Conduct (2010).

2.2.4.2 Recruitment

Recruitment took place between August 2013 and January 2014. Carers were recruited from post-diagnostic support services run within a UK NHS Mental Health Trust. Third Sector support services were also approached, including the Alzheimer's Society as well as independent carer groups.

Support services were attended by the researcher. The study was explained to carers and an opportunity for questions to be asked was provided. Carers were informed that participation was entirely voluntary, that they could withdraw at any time and that their responses would be kept confidential. Questionnaire packs were then handed out to those who were interested. Additional packs were posted to past participants of a local carer course with a covering letter explaining the study (Appendix M).

Each pack was given a unique ID number that linked the questionnaires and the consent forms. Packs contained:

- An information sheet explaining the purpose of the study and what was required of them, including information regarding confidentiality, consent and withdrawal, along with the researcher's contact details (Appendices N and O).
- Two copies of the consent form, one for the carer to sign and date, the other for them to keep with their ID number on (Appendix P).
- A copy of the demographic questionnaire.
- The three measures each with a unique ID number on.

- A stamped addressed envelope, marked private and confidential, addressed to the researcher at Coventry University.
- A slip containing the researchers contact details that participants could distribute to other carers that may have been interested in taking part (Appendix Q).

The questionnaires took approximately 20 minutes to complete and were counterbalanced in the packs to avoid order effects. The short form of each of the measures was selected as they represented less burdensome options for a population with limited time and possibly already under considerable stress. Participants returned one copy of the consent form signed along with the completed demographic questionnaire and the three measures to the researcher in the stamped addressed envelope. Debrief sheets were made available to participants through group facilitators (Appendix R).

A total of 233 packs were disseminated. 75 of these were returned with complete data, representing a response rate of 32.6%. Of these, 2 did not meet inclusion criteria, resulting in the sample of 73 carers.

2.2.4 Analysis

Statistical analysis was performed in SPSS 20 for PC. Pearson's correlation was used to assess the relationships between variables. The criteria described by Baron and Kenny (1986) were used to determine whether coping style mediated the relationship between self-compassion and carer burden. The Sobel z test (1982) was used to assess the significance of the mediation relationship.

2.3 Results

2.3.1 Descriptive statistics

Descriptive statistics are presented in table 2.1. There were no significant differences in the scores between participants of different ages, education level or differing relationship with the care recipient. However, there was a significant difference between scores for men and women on the self-compassion scale ($t_{(69)} = 2.69, p=0.01$) with women scoring significantly less than men. There were no other significant differences between men and women in their scores on other measures.

Table 2.1. Means and standard deviations of study variables

	Self-compassion (SCS-SF)	Emotion-focused Coping	Dysfunctional coping	Carer Burden (ZBI)
Gender				
Male (N=19)	42.89 (7.72)	24.74 (5.13)	19.16 (4.31)	20.74 (9.64)
Female (N=52)	37.31 (8.09)	23.56 (4.91)	20.94 (5.30)	24.71 (8.48)
Relationship to Care Recipient				
Spouse (N=51)	39.61 (8.31)	23.78 (5.10)	20.14 (5.15)	24.41 (9.10)
Child (N=15)	36.80 (8.73)	23.80 (4.68)	20.87 (4.98)	21.27 (8.61)
Sibling (N=2)	35.00 (1.41)	20.50 (6.36)	25.00 (7.07)	20.50 (0.71)
Other (N=3)	37.67 (10.02)	28.00 (1.73)	21.00 (4.36)	24.67 (11.06)
Age				
<65 (N=26)	38.73 (8.40)	23.96 (5.00)	21.54 (5.12)	22.23 (10.11)
66-73 (N=23)	36.65 (7.94)	24.43 (4.69)	22.35 (6.98)	27.48 (7.64)
74+ (N=24)	40.50 (8.31)	23.25 (5.74)	18.67 (4.91)	20.29 (8.48)
Education Level				
None (N=16)	38.06 (7.50)	23.00 (5.05)	21.69 (7.67)	24.63 (9.00)
O Level/GCSE (N=23)	41.78 (9.10)	24.28 (4.67)	19.52 (5.58)	19.48 (9.12)
Higher School Cert. (N=2)	32.50 (2.12)	18.50 (4.95)	22.50 (0.71)	15.00 (21.21)
A Level/School Cert. (N=12)	34.92 (6.17)	24.83 (5.02)	20.83 (3.07)	26.17 (8.46)
Degree (N=12)	39.25 (9.61)	25.00 (6.34)	21.83 (5.36)	27.50 (5.84)
Other (N=8)	37.13 (6.90)	22.13 (4.58)	21.13 (7.59)	22.63 (9.78)

2.3.2 Correlation analysis

Pearson's correlations between the study variables are presented in table 2.2.

Results of the correlation analysis support the first hypothesis, that self-compassion would be negatively related to carer burden. In the total sample, higher levels of self-compassion were associated with lower levels of carer burden as indicated by the significant negative correlation.

The second and third hypotheses predicted the relationship between self-compassion and coping, suggesting that self-compassion would be positively related to emotion-focused coping strategies and negatively related to dysfunctional coping. These hypotheses were also upheld with results showing that self-compassion was negatively correlated with dysfunctional coping strategies and positively correlated with emotion-focused coping strategies.

Further to the hypothesised findings, it is noteworthy that emotion-focused strategies and dysfunctional strategies were not related to each other and only dysfunctional coping strategies were significantly correlated with carer burden.

Table 2.2. Pearson's Correlations of study variables

Variable	Self-compassion	Emotion-focused coping	Dysfunctional coping	Carer Burden
Self-compassion	1			
Emotion-focused Coping	.303**	1		
Dysfunctional Coping	-.489**	-.028	1	
Carer Burden	-.541**	-.024	.444**	1

**Correlation is significant at the 0.01 level (2-tailed)

2.3.3 Mediation analysis

The fourth hypothesis predicted that both types of coping strategies would mediate the relationship between self-compassion and carer burden. Prior to conducting the regression equations required for Baron and Kenny's (1986) mediation analysis, the data were screened to determine whether they satisfied the assumptions of multiple regression analysis. Cook's D indicated that there were two multivariate outliers which were subsequently removed from the analysis. All other assumptions were met.

Baron and Kenny's (1986) model of mediation is presented as two path diagrams in figure 2.2. For both models, the first step requires the predictor to be significantly related to the outcome. For the total sample, self-compassion significantly predicted carer burden ($\beta = -.61$, $t_{(69)} = 6.35$, $p < .001$). The second step requires the predictor (self-compassion) to be significantly related to the mediators (type of coping). This was met in both models with self-compassion significantly predicting dysfunctional coping strategies and emotion-focused coping strategies. The third step requires the mediators (type of coping strategy) to be significantly related to the outcome (carer burden) after controlling for the effects of the predictor (self-compassion). As can be seen in figure 2.2, this condition was met for dysfunctional coping strategies, but not for emotion-focused coping. Finally, mediation is demonstrated if controlling for the mediator significantly reduces the relationship between the predictor (self-compassion) and the outcome (carer burden) relative to the zero-order correlation. Sobel's z tests whether the decrease in β is statistically significant and is mathematically equivalent to testing the significance

of the mediated pathway. Sobel's z confirms that dysfunctional coping strategies significantly mediated the relationship between self-compassion and carer burden. However, emotion-focused strategies did not. These results only partly confirm the fourth hypothesis of the present study.

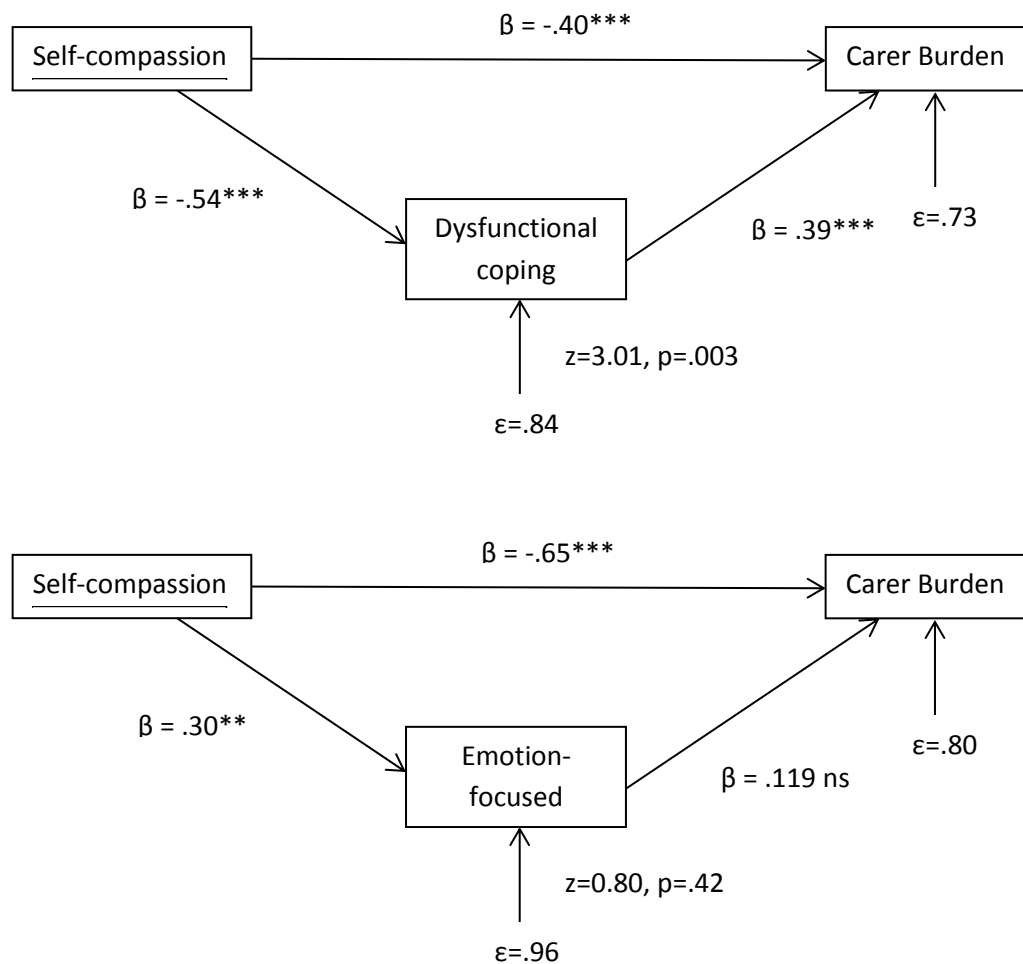


Figure 2.2 Tests of mediations between self-compassion and carer burden with standardised β , error and Sobel's z . $^{***}p < 0.001$, $^{**}p < 0.01$.

2.3.4 Post-hoc analysis

Given the significant difference between males and females scores on the self-compassion scale, mediation analysis was performed grouped by sex. No significant differences were found in terms of standardised beta coefficient values within the models or Sobel's z for the effects of the mediation variables.

2.4 Discussion

The aim of the present study was to explore the relationship between self-compassion, coping strategies and carer burden. Self-compassion was significantly related to carer burden as predicted by the first hypothesis. Carers who reported high levels of self-compassion experienced less carer burden than those lower in self-compassion. The second and third hypotheses were also upheld with higher levels of self-compassion being associated with the use of more emotion-focused coping strategies and fewer dysfunctional coping strategies and vice versa. The final hypothesis, that the relationship between self-compassion and carer burden would be mediated by the type of coping strategy used was partly upheld. Dysfunctional strategies were shown to be a mediator whereas emotion-focused strategies were not. These results demonstrate that carers who have higher levels of self-compassion are more likely to use adaptive emotion-focused strategies and less likely to use dysfunctional ones. However, only the use of dysfunctional coping strategies contributed to increased feelings of carer burden. Higher levels of self-compassion reduce the likelihood of these strategies being used, protecting carers from increased burden.

The results of the present study are consistent with Pearlin et al.'s (1990) stress-process model described in figure 2.1. The impact of the stress of the caregiving role is mediated by the coping strategies employed to manage it. Specifically, the use of dysfunctional strategies leads to increased feelings of burden. The present study has demonstrated that self-compassion influences these coping resources and therefore could be considered to be a background factor within this model.

Previous research has shown that high levels of self-compassion can buffer people from the effects of stress (Neff, et al., 2007). This is the first study to show the significant relationship between self-compassion and carer burden. Self-compassion appears to protect caregivers from the burden associated with caring.

The finding that self-compassion predicts the use of more emotion-focused coping strategies and fewer dysfunctional ones supports previous research. Neff and colleagues (2005) found that students with higher levels of self-compassion responded to a perceived academic failure with more emotion based strategies such as acceptances and positive reframing and fewer dysfunctional avoidant strategies. The current research extends this finding by establishing that the relationship between self-compassion and coping strategies exists in participants of a broader ranges of ages and education levels and when the stressor is ongoing, as it is in the caregiving situation.

Only dysfunctional strategies were found to mediate the relationship between self-compassion and carer burden. Emotion-focused strategies were not related to carer burden or to dysfunctional strategies. This is not consistent with previous research which has found emotion-focused strategies to correlate significantly with both dysfunctional strategies and carer burden (Cooper, Katona & Livingstone, 2008; Cooper, Katona, Orrell et al., 2008). However, the same research also demonstrated that emotion-focused strategies tend to behave differently to other types of coping strategy in terms of their relationships with carer burden and other caregiving factors. Therefore further research exploring emotion-focused strategies is warranted.

2.4.1 Limitations

The present study used an opportunity sample of carers and therefore may not be representative of all caregivers. Furthermore, the overwhelming majority of participants were White British in ethnicity and therefore the findings of this study may not generalize to carers of other ethnic backgrounds.

The present study also relied on self-report measures and therefore could have been affected by socially desirable responding. In addition, caregivers were not asked about how they cope in specific situations. Instead the brief COPE is a general measure of coping and therefore responses given may not accurately represent carer behaviour (Skinner et al., 2003).

The decision was taken not to include a measure of problem-focused strategies as there was limited evidence linking them to self-compassion and carer burden. However, in light of the non-significant results regarding the relationship between emotion-focused strategies and dysfunctional coping and carer burden it may have been helpful to include this to gain a clearer understanding of the broader range of coping strategies employed by carers in this sample.

A general criticism that has been raised with regard to caregiver research is that carers are often treated as a homogenous group, when there are often significant within group differences (Gottlieb & Wolfe, 2002). The current study attempted to overcome this by only recruiting caregivers of people with dementia and collecting caregiver demographic information to account for possible confounding variables. However, not all potentially confounding variables could be covered. In particular, it

would have been helpful to have recorded length of time caring as this is likely to have an impact on level of burden and coping strategies employed.

Finally, the current study employed a cross-sectional design and therefore it is not possible to fully demonstrate causality. The use of the mediational model is considered causal modelling and relies on the variables being arranged in the right order. This can be theory driven and also inferred from previous research. The model presented in the current study is in line with Pearlin and colleagues' (1990) stress-process model. Furthermore, self-compassion has been shown to be related to coping strategies (Neff et al., 2005) and both types of coping strategies have been causally related to carer burden (Kneebone & Martin, 2003). Therefore, it seems likely that the causality chain was correctly laid out in the mediation analysis for the present study.

2.4.2 Clinical implications

The finding that self-compassion is significantly related to carer burden highlights an opportunity for both assessment and intervention in clinical work with caregivers of people with dementia. Low levels of self-compassion could represent a useful indicator of people currently experiencing high levels of burden or those at risk of becoming burdened. Therefore, introducing an assessment of carer self-compassion could provide useful information about current or future support needs.

In terms of intervention, compassion-based therapies are becoming increasingly recognised as a helpful and accessible means of supporting people with a wide

variety of clinical presentations (Gilbert & Proctor, 2007). These aim to help people to develop a more self-compassionate mind-set and could be a useful intervention for carers of people with dementia. Furthermore, the finding that dysfunctional strategies mediate the relationship between self-compassion and carer burden suggests that treatment packages that aim to reduce the use of dysfunctional coping strategies could also be an effective way to support carers of people with dementia.

2.4.3 Research implications

Further research exploring the relationships between self-compassion and other variables within the stress-process model could be a useful means of extending this research. In particular, longitudinal studies would be helpful to confirm the direction of causality of the variables. Further research is also needed to explore the conceptualisations, definitions and relationships of the different coping strategies to ascertain why emotion-focused strategies appear to behave differently to other strategies within the stress-process model.

Additionally, it will be important to explore whether or not the relationship between self-compassion and carer burden extends to carers of people with other physical or mental health difficulties. It would also be useful to expand this study to carers of different ethnic backgrounds. Research has shown that, generally, people from non-white ethnic backgrounds tend to appraise caregiving as less stressful than their white counterparts (Janevic & Connell, 2001). It would be interesting to explore the role of self-compassion in the differing experiences.

2.5 Conclusion

The present study aimed to explore the relationship between self-compassion, coping strategies and carer burden. The results provide the first indication that self-compassion is related to carer burden and that this relationship is mediated, at least in part, by the influence of dysfunctional coping strategies. More research is needed to explore the role of self-compassion in carers of people with a range of physical and mental health difficulties as well as in carers of different ethnic backgrounds. However, the present findings provide a useful starting point from which to begin to develop compassion-based assessments and interventions for carers, which could serve to reduce feelings of burden and enable carers to continue in their role in a way that is manageable for both themselves and the person they care for.

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Chapter 3: Reflective Paper

Reflections on research methods and their meaning to participants and clinicians in healthcare settings

Written in preparation for submission to *Reflective Practice* (see appendix S for author instructions).

Overall chapter word count (excluding references): 3957

3.1 Introduction

Within this thesis I have reviewed the qualitative literature on the positive aspects of caregiving in dementia and undertaken a quantitative piece of research exploring the relationship between self-compassion, coping strategies and carer burden. This final paper provides an opportunity to reflect on the process of completing these two pieces of work. Completing this thesis has given me an insight into the contrast between qualitative and quantitative research methods in terms of their meaning to clinicians, researchers and participants. It is this contrast that will be the focus of this reflective paper. I will begin with my experiences of selecting research methods before moving onto further reflections.

3.2 My experience of choosing methods

I was in a minority within our cohort of trainee clinical psychologists in choosing to undertake a quantitative piece of research; the majority of our year group chose to use qualitative methods and this has been a recurring pattern within recent years. In an ideal world, the research question drives the choice of methodology, but in reality, it is more complex and different people are drawn to different areas. Reflecting on this, I was drawn to the security and certainty that quantitative methods provided. There were rules to follow, sample size calculations to complete and questionnaires that could be used. Results were either significant or they were not and irrespective of the result, I felt I would be able to explore the findings within my discussion. Whilst I find statistics challenging, I had the sense that once I was able to discern which statistical analysis was appropriate, I could learn how to

use SPSS to fully determine the significance and make sense of the subtleties of my data.

This division within our cohort between the two methodologies was apparent from the outset. I recall a discussion with a fellow trainee about our respective research projects early on within the research journey. Their view was that as a psychologist, it is part of our role to advocate for the experiences and views of our clients through our research and the best way to do this is through qualitative methods. According to this perspective, quantitative methods were the territory of the medical profession who strive for black and white answers, whereas we psychologists spend our time battling to understand the grey areas of our clients' experiences. Whilst this was only one person's opinion, it did make me think about my motivation for choosing quantitative methodology. Did it suggest that I was comfortable reducing people's experiences down to a series of black and white numbers and percentages and if so, was this a problem in my approach to understanding human experience within clinical psychology?

As a trainee clinical psychologist, I can see the appeal of conducting qualitative research as in many ways it fits with our identities as clinicians. The in-depth interviews require many of the same engagement and relational skills that are used clinically. The analysis provides an opportunity to explore participant's experiences intimately in a process that feels similar to the development of a formulation. Furthermore, the aim of enhancing understanding and of promoting the individual corresponds with the goals of therapy. Finally, it does not require the use of statistics, the bane of many a trainee's existence.

Quantitative methods, by contrast, can seem colder and more impersonal as the aim is to achieve an objective measure of facts. Data is collected through questionnaires or other means which provide a barrier between researcher and participant. In many ways, it feels like there is an opposition to emotion in quantitative research, a sense that emotional responses need to be separated out from the research process as though they are some unhelpful confounding variable. I wondered whether for some researchers, the appeal of quantitative methods was that they can distance themselves from the difficult emotional responses that arise when conducting research in mental health settings and I can see how it might be difficult to reconcile this with our clinical instincts.

Initially following the conversation with my colleague, I felt that I became defensive, as though I had to justify why I had chosen the way I had. These issues played on my mind and the interaction left me feeling as though in some way I was not doing 'proper' psychological research. I remember thinking this was odd as traditionally, quantitative research has been held in higher esteem than qualitative research and I began considering what these different research methods mean to us as clinical psychologists.

Having now completed my research, I am happy that I chose the approach I did and feel that I am in a good position to reflect further on these issues. In particular, I will consider the impact of the different methodologies on the participants involved in research and also how we go about conducting and utilising varied research in health care settings.

3.3 Representing participants in research

I was particularly interested in my colleague's belief that qualitative methods were the only way to advocate for the views and experiences of our clients. This made me think about how the different methodologies represent the experiences of participants.

Qualitative research is based on an interpretative perspective which views reality as subjective and socially constructed. The main aim of many qualitative methodologies is to gain an understanding of an experience from an insider's perspective (Creswell, 2012) and as such, they appear to lend themselves much more readily to representing participants. The individual is viewed as the expert on their experience. In-depth interviews or observations are conducted and the results sections of qualitative studies are illustrated with direct quotes from the participants, literally giving them a voice. The focus is on the individual and their experience and the whole research process is collaborative. I thoroughly enjoyed the qualitative papers I reviewed in my literature review as they brought to life the positive aspects of caregiving in a vibrant and touching way.

With this in mind I can appreciate why my colleague felt that quantitative methods do not represent participants as well as qualitative research as they do not provide a voice to participants in quite the same way. Quantitative research is founded in a positivist perspective which views the world as a set of facts that can be objectively measured (Barker, Pistrang & Elliott, 2002). There can be tight inclusion and exclusion criteria in studies which enable participants to be generalised into groups that differ only in ways important to the research. Within this, there is no room for

the individual and it can seem like participants are almost treated as a commodity, each one recruited is just another one closer to the total sample required.

There were times when I struggled with this during my research. Carers were often keen to tell me their stories when I went to carers groups and some wrote extra pieces of information on the questionnaires to provide context for their answers.

One lady responded to a question regarding her educational background that 'life is the best education' but ticked that she had gained no formal qualifications. Another gentleman wrote on the self-compassion scale in response to questions asking how tolerant he was of those aspects of his personality that he disliked that he 'liked his personality!' These stories and extra responses were valuable and helped to build a sense of the person. However, I was unable to capture this in my results and it left me feeling as though I was being cold and dismissive, as if I was doing my participants an injustice in some way.

However, on reflection, I came to realise that the motivation behind this aspect of quantitative methodology is misunderstood. It is not through a lack of respect that studies are controlled in this way. It is not that individual participants are not valued; it is more that as a group their contribution to research is greater than the sum of their parts. Through not collecting these extra personal pieces of information, I was able to recruit the large number of participants needed for the study. By recruiting a large group of carers, I was able to detect the significant results in my study and it is through these significant results that I could accurately represent the experiences of my participants and that of carers more generally. It may not be their voices per se describing their experiences, but the numbers still

tell their story. The injustice to my participants would have come if I had not reached the sample size I needed, perhaps through being distracted by the subtle extra pieces of information, resulting in less definite conclusions, or missing the significant results entirely.

Furthermore, the scientist-practitioner nature of the role means that we clinical psychologists are well placed to communicate the experiences of our participants regardless of the format of the data. Whereas some researchers may prefer quantitative methods as they provide an opportunity to separate themselves from the emotions present in mental health settings, our clinical skills mean that we are able to hold onto and contain these. Whilst I was not literally able to record the contextual pieces of information provided, I feel I was able to use these experiences with my clinical knowledge to represent the carers who participated in my research in a sensitive and thoughtful manner.

Alongside this, I also considered the type of person that might engage with either qualitative or quantitative research. Clearly based on my own experiences there were some of my participants who were happy to give extra detail, but there were many more who seemed content with filling out an anonymous questionnaire. It can be a big commitment to undertake a qualitative interview. Not only does it take time, but it can take confidence and emotional investment to share your feelings and story with a stranger. This is not something that everyone will be comfortable doing.

The positive aspect of being able to utilise both methods in research in psychology is that they allow all types of people to express themselves in a manner in which

they feel comfortable. Whilst quantitative methods may not provide the level of personal detail that qualitative studies do, they enable those who do not feel able to provide this detail to contribute to research. As my colleague commented, part of our role is to enable and advocate for the people we work with through our research; however, this should not be limited to those who can commit to and articulate themselves during an in-depth interview, but should apply to all of those with whom we work.

It is not as simple as one methodology being better than another at representing participants. It is more about focusing on the aim of the research and ensuring that the project is carried out in the most suitable and respectful way possible for those who take part. I feel that what clinical psychologists bring as scientist-practitioners is the ability to hold in mind the participants and the feelings involved in the research regardless of the methodology. I would even go as far as to suggest that we may need to make a more conscious effort to utilise our clinical skills and knowledge with quantitative research to ensure that participants are represented in the best way possible.

3.4 Conducting and utilising research in healthcare settings

Undertaking my thesis has also highlighted to me that, as scientist-practitioners, clinical psychologists are in a unique position being both consumers of and generators of research. Therefore, I feel that we have a responsibility not just to conduct research, but to support its utilisation in our own clinical practice and that of our colleagues. In many ways our skills mean that we are well placed to support with this process. We have the ability to critically appraise research whilst also

having an in-depth understanding of the type of clients who present to mental health services along with the knowledge of the practical limitations that the services have. Furthermore, we are also trained to utilise both quantitative and qualitative research methods and appreciate the contribution of both to clinical practice.

However, completing this thesis has also demonstrated to me that we do not always make use of these skills. It can be easy to become stuck and almost 'blinkered' in our approach to research, limiting the scope of what we can do and use. In particular, there appear to be contextual pressures that affect our attitudes towards research. These include the opinions of our peers, the influence of the wider research context and the impact of health care settings.

3.4.1 The influence of peers

As a wealth of social psychology research has demonstrated, we can be very much influenced by those around us (e.g. Asch, 1952). I found myself caught up in this process within the interaction with my colleague described earlier. At the time, I perceived this colleague to be dismissing my research and I took this personally. I became quite angry and found myself wanting to 'prove' that quantitative methods were 'better' than qualitative methods. I was surprised by the strength of my reaction and this made me realise that we have a lot invested in our projects, both in terms of time and emotion.

In considering this, I was reminded of Festinger's (1957) cognitive dissonance theory. Cognitive dissonance refers to the discomfort that can be experienced when

encountering information that challenges one's own beliefs. According to the theory, we try to avoid cognitive dissonance where possible, but when faced with it we attempt to reduce it through manipulating or denying the alternative evidence we are presented with. The points my colleague raised challenged my beliefs about the value of my research and so it seems likely that my defensive response was an attempt to reduce the cognitive dissonance I experienced.

In some respects, I feel we need to hold onto a strong belief in our work to ensure that the research we do undertake is conducted to the highest standard. However, we need to be mindful of how these views can influence our actions and be influenced by those around us. Beck (1995) has highlighted that we have a tendency to be biased towards information that supports our views and this, coupled with the effects of cognitive dissonance could result in us neglecting or rejecting valuable alternative perspectives. It seems particularly important to be mindful of this when considering the influence of the wider research context and healthcare settings as both can have a strong impact on us.

3.4.2 The influence of the wider research context

Within the wider research context, there has been tension between qualitative and quantitative research in psychology. Traditionally, quantitative methods and their results tend to be given more weight than qualitative results. Quantitative research provides firm, objective conclusions and there remains a distrust of the less concrete conclusions presented by qualitative research. It seems that quantitative methods fit better with the dominant discourse of our society in offering more certainty and guidance in what we should do. They certainly tend to be the

preference of many of our colleagues from other healthcare disciplines who are not exposed to qualitative research in the same way that we are.

It can therefore feel like an uphill battle to demonstrate the value of qualitative research to colleagues. The findings can seem vague, especially to medical professionals who are embedded in a culture of 'doing' rather than 'understanding'. In fact, I found myself pulled into this mind-set at times whilst writing my literature review. I read 14 qualitative papers which had clearly taken a huge amount of time and effort to complete, yet I felt frustrated as I could not draw definitive conclusions. Part of what I concluded was that quantitative research was needed to further define measures and operationalise the themes identified. Whilst I was able to step back and recognise that the depth of understanding provided by the qualitative papers I reviewed was a valuable finding in its own right, I wondered if my medical, nursing or social work colleagues would be able to do the same. I realised how dominant the desire for solid conclusions can be and how easy it can be to dismiss qualitative findings. This further reinforced for me how clinical psychologists have a valuable role and responsibility to educate and communicate with colleagues with regard to research and the understanding and value of the two modalities.

3.4.3 The influence of healthcare settings

The mental health system within the NHS has been dominated by the medical model for the majority of its existence. This holds at its core that mental health difficulties can be studied, understood and treated through the same techniques and tools as physical health problems. Within this approach, mental health

problems are assumed to arise through faulty physiological or psychological processes that occur within the person. These faulty processes display themselves as sets of symptoms which can be identified, labelled and cured with specific interventions. According to this model of understanding, these problems are not influenced by the person's context, but instead occur independently of their relationships, values and culture (for example, see Harmful Dysfunction Analysis (HDA), Wakefield, 1992).

However, the medical model is disputed by many in psychology and psychiatry who advocate for a broader understanding of psychological difficulties (Moncrieff, 2010). Psychological models of mental health seek to understand the mechanisms and factors which underpin a person's distress. Within these models, people's 'presenting problems' are not assumed to be independent of their experiences, but are seen to be very much influenced by the context of their beliefs, relationships and values. Similarly, recovery is not simply the alleviation of symptoms, but is a far more complex and individual process involving the development of positive self-identity (Leamy, Bird, Le Boutillier, Williams & Slade, 2011). This perspective does not deny the influence of biological factors in mental health difficulties, but instead highlights that these are one of many elements that are involved in complex and dynamic process that underlie the problems experienced (Bracken et al., 2012).

The idea that mental health difficulties could be understood through the same paradigm as physical health problems is a powerful one and one supported by many of our colleagues. It would be incredible to think that the distress and suffering caused by mental health difficulties could be alleviated through a

mechanism similar to the one through which antibiotics treat an infection.

Therefore, within psychology, the drive has been to develop therapies that work to 'cure' peoples' symptoms.

It is also within this framework that the National Institute for Health and Clinical Excellence (NICE) guidelines are developed. These guidelines outline the recommended treatments for both physical and mental health difficulties. They are followed by all services within the NHS and are based on up-to-date research. This system holds traditional views around what is considered valid scientific evidence. Quantitative research is favoured and the randomised control trial (RCT) is considered the gold standard research method. The RCT has many advantages. It is a robust method that is well suited to demonstrating the efficacy of interventions.

However, despite being robust, relying on the RCT can be somewhat limiting. RCTs lend themselves well to testing the efficacy of interventions that are clearly structured and can be delivered consistently across patients in the same way as medication would be in a drug trial (Ashcroft, 2004). However, not all therapies can be delivered in this way. Furthermore, there are often tight inclusion and exclusion criteria for participants. This means that it can be difficult to generalise the findings to those who fall outside these criteria and it is these people who are likely to present to services (Kazdin, 2008). It therefore seems that the evidence considered by NICE can give a narrow and skewed perspective of what might be the most appropriate interventions for people with particular difficulties.

Those who support psychological models of mental health argue against the reliance on RCTs and in favour of broadening the view of what is considered

‘scientific evidence’ to include qualitative research and less favoured quantitative methods such as single-case studies (Kazdin, 2008). They suggest that these methods allow a more detailed exploration of therapies and interventions that do not lend themselves to being studied through RCTs. They also highlight that this research can shed light on the experiences of people who fall outside the tight controls of the RCTs to further understand the mechanisms by which certain therapies work for certain people and not others.

Within this context, it can be easy to get drawn into taking sides and potentially favouring particular methodologies because of the model of mental health with which they are associated. However, what I have learned is that we need a balance of research in order to inform our clinical practice. RCTs provide useful information about the efficacy of therapies. However, they tell us less about the effectiveness of these therapies in everyday practice with the people who present to services. Therefore we need to use other types of research or information to make decisions about the best way to support that person. Maintaining this balanced perspective can be difficult and frustrating in a context in which one particular viewpoint is dominant. However, rather than being influenced by this context, as psychologists, we have the necessary skills to work towards and support our colleagues to take a more balanced perspective on research.

3.4.4 Reflective practice

As clinical psychologists, one of our most significant strengths is our use of reflective and reflexive practice. Reflective practice is the successive process of analysing and reanalysing important episodes of activity, drawing on multiple levels

of representation. Reflexivity is the process of being aware, in the moment, of our thoughts, feelings and motivations for acting in a particular situation (Dallos & Stedmon, 2009). Engaging in these processes enables us not only to learn from previous experiences and but also to draw on theory and knowledge to inform our ongoing engagement in particular situations. We are used to using these skills with regard to our clinical work. However, they could also be usefully encouraged and applied to research settings. Specifically, they can be used to appreciate the complexity of dynamics at work within healthcare settings and bring a more thoughtful and measured approach to the research environment. Furthermore, we can support our colleagues to do the same and ensure we make the most of the research opportunities available to us.

3.5 Conclusion

Overall, completing this project has taught me far more than just practical research skills. It has given me an insight into the complex world of clinical research and helped me to appreciate the different contributions of qualitative and quantitative research methods. I have learned that there is a significant amount to hold in mind when conducting research in clinical settings from the experiences of the participants to the views of colleagues, the wider context of research and the NHS. It can be very easy to be pulled into conflict and lose sight of the primary aim of research which is to contribute new knowledge that furthers our understanding of what it is to be human and enables us to support our clients in the most appropriate way.

However, I have also learned that as clinical psychologists, we are very well placed to stand aside from these complex situations. As scientist-practitioners and reflective practitioners, we have a wealth of skills that give us a different insight from many of our colleagues into the value of research and its importance in clinical practice. Therefore, I feel we have a responsibility to use these skills to represent participants in the best way and also support our colleagues through the research process. This is something that I aim to carry forward in my ongoing career as a clinical psychologist.

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Appendix A

Author instructions for *Dementia*



Dementia

The International Journal of Social Research and Practice

Manuscript Submission Guidelines

Dementia publishes original research or original contributions to the existing literature on social research and dementia. The journal acts as a major forum for social research of direct relevance to improving the quality of life and quality of care for people with dementia and their families.

Article types

Dementia welcomes original research or original contributions to the existing literature on social research and dementia.

Dementia also welcomes papers on various aspects of innovative practice in dementia care. Submissions for this part of the journal should be between 750-1500 words.

The journal also publishes book reviews

Manuscript style

File types

Only electronic files conforming to the journal's guidelines will be accepted. Preferred formats for the text and tables of your manuscript are Word DOC, DOCX, RTF, XLS. LaTeX files are also accepted. Please also refer to additional guideline on submitting artwork [and supplemental files] below.

Journal Style

Dementia conforms to the SAGE house style.

Lengthy quotations (over 40 words) should be displayed and indented in the text.

Language and terminology. Jargon or unnecessary technical language should be avoided, as should the use of abbreviations (such as coded names for conditions). Please avoid the use of nouns as verbs (e.g. to access), and the use of adjectives as nouns (e.g. dements). Language that might be deemed sexist or racist should not be used.

Abbreviations. As far as possible, please avoid the use of initials, except for terms in common use.

Please provide a list, in alphabetical order, of abbreviations used, and spell them out (with the abbreviations in brackets) the first time they are mentioned in the text.

Reference Style

Dementia adheres to the APA reference style.

Manuscript Preparation

The text should be double-spaced throughout with generous left and right-hand margins. Brief articles should be up to 3000 words and more substantial articles between 5000 and 8000 words (references are not included in this word limit). At their discretion, the Editors will also consider articles of greater length. Innovative practice papers should be between 750-1500 words.

Keywords and Abstracts: Helping readers find your article online

The title, keywords and abstract are key to ensuring readers find your article online through online search engines such as Google. Please refer to the information and guidance on how best to title your article, write your abstract and select your keywords by visiting SAGE's Journal Author Gateway Guidelines on [How to Help Readers Find Your Article Online](#). The abstract should be 100-150 words, and up to five keywords should be supplied in alphabetical order.

Corresponding Author Contact details

Provide full contact details for the corresponding author including email, mailing address and telephone numbers. Academic affiliations are required for all co-authors. These details should be presented separately to the main text of the article to facilitate anonymous peer review.

Guidelines for submitting artwork, figures and other graphics

For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's [Manuscript Submission Guidelines](#).

Figures supplied in colour will appear in colour online regardless of whether or not these illustrations are reproduced in colour in the printed version. For specifically requested colour reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

Appendix B

Quality Ratings Checklist

	Criteria	Score
1	Is there a clear connection to an existing body of knowledge/wider theoretical framework?	Yes = 1, No = 0
2	Are research methods appropriate to the question being asked?	Yes = 1, No = 0
3	Is the description of the context for the study clear and sufficiently detailed?	Yes = 1, No = 0
4	Is the description of the method clear and sufficiently detailed to be replicated?	Yes = 1, No = 0
5	Is there an adequate description of the sampling strategy?	Yes = 1, No = 0
6	Is the method of data analysis appropriate and justified?	Yes = 1, No = 0
7	Are procedures for data analysis clearly described and in sufficient detail?	Yes = 1, No = 0
8	Is there evidence that data analysis involved more than one researcher?	Yes = 1, No = 0
9	Are the participants adequately described?	Yes = 1, No = 0
10	Are the findings presented in an accessible and easy to follow manner?	Yes = 1, No = 0
11	Is sufficient original evidence provided to support the relationship between interpretation and evidence?	Yes = 1, No = 0
Maximum possible score 11 and minimum 0.		

Appendix C

Author instructions for *Aging and Mental Health*



Aging & Mental Health

Instructions for authors

SCHOLARONE MANUSCRIPTS™

This journal uses ScholarOne Manuscripts (previously Manuscript Central) to peer review manuscript submissions. Please read the [guide for ScholarOne authors](#) before making a submission. Complete guidelines for preparing and submitting your manuscript to this journal are provided below.

Aging & Mental Health is an international peer-reviewed journal publishing high-quality, original research. All submitted manuscripts are subject to initial appraisal by the Editor and if found suitable for further consideration, to peer-review by independent anonymous expert referees. All peer review is double blind and submission is online via [ScholarOne Manuscripts](#). We encourage the submission of timely review articles that summarize emerging trends in an area of mental health or aging, or which address issues which have been overlooked in the field. Reviews should be conceptual and address theory and methodology as appropriate.

Aging & Mental Health considers all manuscripts on the strict condition that

- the manuscript is your own original work, and does not duplicate any other previously published work, including your own previously published work.
- the manuscript is not currently under consideration or peer review or accepted for publication or in press or published elsewhere.
- the manuscript contains nothing that is abusive, defamatory, libellous, obscene, fraudulent, or illegal.

Please note that *Aging & Mental Health* uses [CrossCheck™](#) software to screen manuscripts for unoriginal material. By submitting your manuscript to *Aging & Mental Health* you are agreeing to any necessary originality checks your manuscript may have to undergo during the peer-review and production processes.

Any author who fails to adhere to the above conditions will be charged with costs which *Aging & Mental Health* incurs for their manuscript at the discretion of *Aging & Mental Health*'s Editors and Taylor & Francis, and their manuscript will be rejected.

Manuscript preparation

General guidelines

- Manuscripts are accepted only in English. Any consistent spelling and punctuation styles may be used. Please use single quotation marks, except where 'a quotation is 'within' a quotation'. Long quotations of 40 words or more should be indented without quotation marks.
- Manuscripts may be in the form of (i) regular articles not usually exceeding **5,000 words** (under special circumstances, the Editors will consider articles up to 10,000 words), or (ii) short reports not exceeding **2,000 words**. These word limits **exclude** references and tables. Manuscripts that greatly exceed this will be critically reviewed with respect to length. Authors should include a word count with their manuscript.
- Manuscripts should be compiled in the following order: title page (including Acknowledgments as well as Funding and grant-awarding bodies); abstract; keywords; main text; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figure caption(s) (as a list).
- Structured Abstracts of not more than 250 words are required for all manuscripts submitted. The abstract should be arranged as follows: Title of manuscript; name of journal; abstract text containing the following headings: Objectives, Method, Results, and Conclusion.
- Each manuscript should have 3 to 5 keywords.
- Section headings should be concise. The text should normally be divided into sections with the headings Introduction, Methods, Results, and Discussion. Long articles may need subheadings within some sections to clarify their content.
- All authors of a manuscript should include their full names, affiliations, postal addresses, telephone numbers and email addresses on the cover page of the manuscript. One author should be identified as the corresponding author. Please give the affiliation where the research was conducted. If any of the named co-authors moves affiliation during the peer review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after the manuscript is accepted. Please note that the email address of the corresponding author will normally be displayed in the article PDF (depending on the journal style) and the online article.
- All persons who have a reasonable claim to authorship must be named in the manuscript as co-authors; the corresponding author must be authorized by all co-authors to act as an agent on their behalf in all matters pertaining to publication of the manuscript, and the order of names should be agreed by all authors.
- Biographical notes on contributors are not required for this journal.
- Authors must also incorporate a Disclosure Statement which will acknowledge any financial interest or benefit they have arising from the direct applications of their research.
- For all manuscripts non-discriminatory language is mandatory. Sexist or racist terms must not be used.
- Authors must adhere to SI units. Units are not italicised.
- When using a word which is or is asserted to be a proprietary term or trade mark, authors must use the symbol ® or TM.
- Authors must not embed equations or image files within their manuscript.

Style guidelines

- [Description of the Journal's article style.](#)
- [Description of the Journal's reference style.](#)
- [Guide to using mathematical scripts and equations.](#)
- [Word templates](#) are available for this journal. If you are not able to use the template via the links or if you have any other template queries, please contact authortemplate@tandf.co.uk.

Figures

- Please provide the highest quality figure format possible. Please be sure that all imported scanned material is scanned at the appropriate resolution: 1200 dpi for line art, 600 dpi for grayscale and 300 dpi for colour.
- Figures must be saved separate to text. Please do not embed figures in the manuscript file.
- Files should be saved as one of the following formats: TIFF (tagged image file format), PostScript or EPS (encapsulated PostScript), and should contain all the necessary font information and the source file of the application (e.g. CorelDraw/Mac, CorelDraw/PC).
- All figures must be numbered in the order in which they appear in the manuscript (e.g. Figure 1, Figure 2). In multi-part figures, each part should be labelled (e.g. Figure 1(a), Figure 1(b)).
- Figure captions must be saved separately, as part of the file containing the complete text of the manuscript, and numbered correspondingly. The captions should include keys to symbols, and should make interpretation possible without reference to the text.
- The filename for a graphic should be descriptive of the graphic, e.g. Figure1, Figure2a.

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Appendix D

Participant demographic questionnaire

Coventry University
Priory Street, Coventry CV1 5FB
Telephone 024 7688 8328
Fax 024 7688 8702

Programme Director
Doctorate Course in Clinical Psychology
Dr Eve Knight
BSc Clin.Psy.D. CPsychol

Participant No: 144

THE UNIVERSITY OF
WARWICK



Participant Information

Please answer all of the following questions. All responses will remain anonymous so please answer as honestly and accurately as you can.

1. Are you male or female?

M or F

2. What age are you?.....

3. To which Ethnic Origin group do you most closely belong: (please tick)

- | | | | |
|---------------------------|--------------------------|------------------|--------------------------|
| Black (Caribbean) | <input type="checkbox"/> | Bangladeshi | <input type="checkbox"/> |
| Black (British) | <input type="checkbox"/> | Black (African) | <input type="checkbox"/> |
| Chinese | <input type="checkbox"/> | Indian | <input type="checkbox"/> |
| Pakistani | <input type="checkbox"/> | White (British) | <input type="checkbox"/> |
| White (European – non UK) | <input type="checkbox"/> | White (European) | <input type="checkbox"/> |
| Prefer not to say | <input type="checkbox"/> | | |

Other (please state).....

Demographic Questionnaire
Self-Compassion, Coping Strategies and Carer Burden in Carers of People with Dementia
Version 1.0 13/12/12

Dean of Faculty of Health and Life Sciences
Dr Linda Merriman Mphil PhD DpodM CertEd Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805
Head of Department of Psychology
Professor James Tresilian BSc PhD University of Warwick Coventry CV4 7AL Tel 024 7657 3009

www.coventry.ac.uk

4. What is the highest qualification you have achieved: (please tick)

None ☐

'O' Level /GCSE ☐

Higher School Certificate ☐

'A' Level / School Certificate ☐

Degree ☐

Other (please state).....

The following questions ask about your caregiving role:

5. Do you consider yourself to be a carer for your friend/relative with dementia?

Yes ☐

No ☐

6. Do you live/reside with the person that you care for?

Yes ☐

No ☐

7. What is your relationship to the person that you care for?

Spouse ☐

Sibling ☐

Child ☐

Friend ☐

Other (please state).....

8. Do you spend 5 or more hours per week in care or support-related activities for the person that you care for?

Yes ☐

No ☐

9. Do you have a physical or mental health difficulty that means that you require more care than the person that you care for?

Yes ☐

No ☐

Thank you for completing these questions.

Appendix E

Self-compassion Scale – Short Form

Coventry University
 Priory Street, Coventry CV1 5FB
 Telephone 024 7688 8328
 Fax 024 7688 8702

Programme Director
Doctorate Course in Clinical Psychology
 Dr Eve Knight
 BSc Clin.Psy.D. CPsychol

THE UNIVERSITY OF
WARWICK



Participant No: 144

HOW I TYPICALLY ACT TOWARDS MYSELF IN DIFFICULT TIMES

Please read each statement carefully before answering. To the right of each item, indicate how often you behave in the stated manner, using the following scale:

	Almost never					Almost always
	1	2	3	4	5	
1. When I fail at something important to me I become consumed by feelings of inadequacy.	1	2	3	4	5	
2. I try to be understanding and patient towards those aspects of my personality I don't like.	1	2	3	4	5	
3. When something painful happens I try to take a balanced view of the situation.	1	2	3	4	5	
4. When I'm feeling down, I tend to feel like most other people are probably happier than I am.	1	2	3	4	5	
5. I try to see my failings as part of the human condition.	1	2	3	4	5	
6. When I'm going through a very hard time, I give myself the caring and tenderness I need.	1	2	3	4	5	
7. When something upsets me I try to keep my emotions in balance.	1	2	3	4	5	
8. When I fail at something that's important to me, I tend to feel alone in my failure.	1	2	3	4	5	
9. When I'm feeling down I tend to obsess and fixate on everything that's wrong.	1	2	3	4	5	

SCS
 Self-Compassion, Coping Strategies and Carer Burden in Carers of People with Dementia
 Version 1.0 13/12/12

Dean of Faculty of Health and Life Sciences
 Dr Linda Merriman MPhil PhD DpodM CertEd Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805

Head of Department of Psychology
 Professor James Trellian BSc PhD University of Warwick Coventry CV4 7AL Tel 024 7657 3009

www.coventry.ac.uk

10.	When I feel inadequate in some way, I try to remind myself that feelings of inadequacy are shared by most people.	1	2	3	4	5
11.	I'm disapproving and judgmental about my own flaws and inadequacies.	1	2	3	4	5
12.	I'm intolerant and impatient towards those aspects of my personality I don't like.	1	2	3	4	5

Appendix F

The brief COPE

Coventry University
Priory Street, Coventry CV1 5FB
Telephone 024 7688 8328
Fax 024 7688 8702

Programme Director
Doctorate Course in Clinical Psychology
Dr Eve Knight
BSc Clin.Psy.D. CPsychol

Participant No: 66

THE UNIVERSITY OF
WARWICK



Brief COPE

These items ask about the ways you've been coping with the stress associated with your caregiving role. There are many ways to try to deal with problems and different people deal with things in different ways. I'm interested in how you try to manage it. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says i.e. how much or how frequently. Don't answer on the basis of whether it seems to be working or not, just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

1 = I haven't been doing this at all

2 = I've been doing this a little bit

3 = I've been doing this a medium amount

4 = I've been doing this a lot

1.	I've been turning to work or other activities to take my mind off things.	1	2	3	4
2.	I've been saying to myself "this isn't real."	1	2	3	4
3.	I've been using alcohol or other drugs to make myself feel better.	1	2	3	4
4.	I've been getting emotional support from others.	1	2	3	4
5.	I've been giving up trying to deal with it.	1	2	3	4
6.	I've been refusing to believe that it has happened.	1	2	3	4

Brief COPE

Self-Compassion, Coping Strategies and Carer Burden in Carers of People with Dementia
Version 1.0 13/12/12

Dean of Faculty of Health and Life Sciences

Dr Linda Merriman Mphil PhD DpodM CertEd Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805

Head of Department of Psychology

Professor James Tressilian BSc PhD University of Warwick Coventry CV4 7AL Tel 024 7657 3009

www.coventry.ac.uk

7.	I've been saying things to let my unpleasant feelings escape.	1	2	3	4
8.	I've been using alcohol or other drugs to help me get through it.	1	2	3	4
9.	I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4
10.	I've been criticizing myself.	1	2	3	4
11.	I've been getting comfort and understanding from someone.	1	2	3	4
12.	I've been giving up the attempt to cope.	1	2	3	4
13.	I've been looking for something good in what is happening.	1	2	3	4
14.	I've been making jokes about it.	1	2	3	4
15.	I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.	1	2	3	4
16.	I've been accepting the reality of the fact that it has happened.	1	2	3	4
17.	I've been expressing my negative feelings.	1	2	3	4
18.	I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4
19.	I've been learning to live with it.	1	2	3	4
20.	I've been blaming myself for things that happened.	1	2	3	4
21.	I've been praying or meditating.	1	2	3	4
22.	I've been making fun of the situation.	1	2	3	4

Brief COPE

Self-Compassion, Coping Strategies and Carer Burden in Carers of People with Dementia
Version 1.0 13/12/12

Appendix G

The Zarit Burden Interview: Short Form

Coventry University
 Priory Street, Coventry CV1 5FB
 Telephone 024 7688 8328
 Fax 024 7688 8702

Programme Director
Doctorate Course in Clinical Psychology
 Dr Eve Knight
 BSc Clin.Psy.D., CPsychol
 Participant No: 144

THE UNIVERSITY OF
WARWICK



THE ZARIT BURDEN INTERVIEW – Short Form

Please circle the response the best describes how you feel. All answers and anonymous so please be as honest as you can.

	Never	Rarely	Some times	Quite Frequently	Nearly Always
1. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0	1	2	3	4
2. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4
3. Do you feel angry when you are around your relative?	0	1	2	3	4
4. Do you feel that your relative currently affects our relationships with other family members or friends in a negative way?	0	1	2	3	4
5. Do you feel strained when you are around your relative?	0	1	2	3	4
6. Do you feel your health has suffered because of your involvement with your relative?	0	1	2	3	4

ZBI

Self-Compassion, Coping Strategies and Carer Burden in Carers of People with Dementia
 Version 1.0 13/12/12

Dean of Faculty of Health and Life Sciences

Dr Linda Merriman Mphil PhD DpodM CertEd Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805

Head of Department of Psychology

Professor James Trellian BSc PhD University of Warwick Coventry CV4 7AL Tel 024 7657 3009

www.coventry.ac.uk

	Never	Rarely	Some times	Quite Frequently	Nearly Always
7. Do you feel that you don't have as much privacy as you would like because of your relative?	0	1	2	3	4
8. Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4
9. Do you feel you have lost control of your life since your relative's illness?	0	1	2	3	4
10. Do you feel uncertain about what to do about your relative?	0	1	2	3	4
11. Do you feel you should be doing more for your relative?	0	1	2	3	4
12. Do you feel you could do a better job in caring for your relative?	0	1	2	3	4

ZBI

Self-Compassion, Coping Strategies and Carer Burden in Carers of People with Dementia
Version 1.0 13/12/12

Appendix H

Confirmation of Coventry University ethical approval

Self-Compassion and Coping Strategies: An exploration of the relationship to burden in carers of people with dementia
P8338

**REGISTRY RESEARCH UNIT
ETHICS REVIEW FEEDBACK FORM**

(Review feedback should be completed within 10 working days)

Name of applicant: Joanna Lloyd.....

Faculty/School/Department: [Faculty of Health and Life Sciences] Clinical Psychology

Research project title: Self-Compassion and Coping Strategies: An exploration of the relationship to burden in carers of people with dementia

Comments by the reviewer

1. Evaluation of the ethics of the proposal:

The changes have been made well.

2. Evaluation of the participant information sheet and consent form:

The debrief is now fine. It could be worth adding websites as well as phone numbers to the sources of support (especially as one sounds like a website anyway) but this isn't necessary for approval.

3. Recommendation:

(Please indicate as appropriate and advise on any conditions. If there are any conditions, the applicant will be required to resubmit his/her application and this will be sent to the same reviewer).

- | | |
|--|---|
| <input checked="checked" type="checkbox"/> | Approved - no conditions attached |
| <input type="checkbox"/> | Approved with minor conditions (no need to re-submit) |
| <input type="checkbox"/> | Conditional upon the following – please use additional sheets if necessary (please re-submit application) |
| <input type="checkbox"/> | Rejected for the following reason(s) – please use other side if necessary |
| <input type="checkbox"/> | Not required |

Name of reviewer: Anonymous

Date: 15/03/2013

Appendix I

Confirmation of local NHS Research Ethics Committee approval



Health Research Authority

NRES Committee West Midlands - Coventry & Warwickshire

The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Telephone: 0115 8839311
Facsimile: 0115 8839294

14 June 2013

Miss Joanna Lloyd
Department of Clinical Psychology
Coventry University
James Starley Building, Priory Street
CV1 5FB

Dear Miss Lloyd

Study title:	Self-compassion and coping strategies: An exploration of the relationship to burden in carers of people with dementia
REC reference:	13/WM/0200
IRAS project ID:	120849

Thank you for your letter of 10th June 2013 I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 06 June 2013

Documents received

The documents received were as follows:

Document	Version	Date
Covering Letter		10 June 2013
Participant Information Sheet: NHS Version	2	10 June 2013
Participant Information Sheet: non NHS version	2	10 June 2013

Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	Version	Date
Covering Letter		26 April 2013
Covering Letter		10 June 2013
Evidence of insurance or indemnity	Allianz and AON	01 August 2012
Investigator CV	1	22 April 2013
Letter from Sponsor		03 April 2013

Other: Non-NHS SSI	120849/443671/7/404/199641/270722	26 April 2013
Other: CV - Dr Tom Patterson		14 May 2012
Other: CV - Jane Muers		30 March 2013
Other: Participant Debrief Sheet	1.0	14 March 2013
Other: Recruitment Slip	1.0	13 December 2012
Other: Withdrawal Slip	1.0	13 December 2012
Other: Coventry University Ethics comments		26 April 2013
Other: Coventry University Ethics Review Form		15 March 2013
Participant Consent Form: Self-Compassion, Coping Strategies and Carer Burden in Carers of People with Dementia	1.0	13 December 2012
Participant Information Sheet: Self-Compassion, coping strategies and carer burden in carers of people with dementia	1.0	14 March 2013
Participant Information Sheet: NHS Version	2	10 June 2013
Participant Information Sheet: non NHS version	2	10 June 2013
Protocol	1.0	13 December 2012
Questionnaire: Demographic Questionnaire	1.0	13 December 2012
Questionnaire: Brief COPE	1.0	13 December 2012
Questionnaire: Self Compassion Scale	1.0	13 December 2012
Questionnaire: Zarit Burden Interview	1.0	13 December 2012
REC application	120849/443668/1/976	26 April 2013

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

13/WM/0200	Please quote this number on all correspondence
------------	--

Yours sincerely



Miss Andrea Graham
Committee Co-ordinator

E-mail: nrescommittee.westmidlands-coventryandwarwick@nhs.net

Copy to: *Miss Joanna Lloyd,*
Ms Kelly Spencer, Coventry and Warwickshire Partnership Trust

Appendix J

Updated confirmation of local NHS Research Ethics Committee approval



Health Research Authority

NRES Committee West Midlands - Coventry & Warwickshire

The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Tel: 0115 8839435
Fax: 0115 8839294

28 August 2013

Miss Joanna Lloyd
Department of Clinical Psychology
Coventry University
James Starley Building, Priory Street
CV1 5FB

Dear Miss Lloyd

Study title:	Self-compassion and coping strategies: An exploration of the relationship to burden in carers of people with dementia
REC reference:	13/WM/0200
Amendment number:	1
Amendment date:	10 August 2013
IRAS project ID:	120849

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Covering Letter		13 August 2013
Notice of Substantial Amendment (non-CTIMPs)	1	10 August 2013
Recruitment Letter	2	28 August 2013

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

13/WM/0200:

Please quote this number on all correspondence

Yours sincerely

A handwritten signature in black ink, appearing to be 'H. Brittain', with a large loop and a trailing flourish.

Dr Helen Brittain
Chair

E-mail: NRESCommittee.WestMidlands-CoventryandWarwick@nhs.net

Enclosures: *List of names and professions of members who took part in the review*

Copy to: *Ms Kelly Spencer, Coventry and Warwickshire Partnership Trust*
Miss Joanna Lloyd

Appendix K

Confirmation of Coventry and Warwickshire Partnership Trust Research and Development team ethical approval

Coventry and Warwickshire Partnership Trust

West Midlands (South) Comprehensive Local Research Network
Fourth Floor, West Wing (ACF40002)
University Hospitals Coventry & Warwickshire NHS Trust
University Hospital
Clifford Bridge Road
Coventry
CV2 2DX

17th July 2013

Miss J Lloyd
Department of Clinical Psychology
Coventry University
James Stirling Building
Priory Street
CV1 5FB

Dear Miss Lloyd

Project Title: Self Compassion and coping strategies: An exploration of the relationship to burden in carers of people with dementia.
R&D Ref: PAR250313
REC Ref: 13/WM/0200

I am pleased to inform you that the R&D review of the above project is complete, and NHS permission has been granted for the study at Coventry and Warwickshire Partnership NHS Trust. The details of your study have now been entered onto the Trust's database.

The permission has been granted on the basis described in the application form, protocol and supporting documentation. The documents reviewed were:

Document	Version	Date
REC Favourable Opinion Letter	13/WM/0200	14.06.2013
Research Proposal	1.0	13.12.2012
Participant Information Sheet NHS Version	2.0	10.06.2013
Consent Form	1.0	13.12.2012
Withdrawal Slip	1.0	13.12.2012
Participant de brief sheet	1.0	14.03.2013
The Zarit Burden Interview	1.0	13.12.2012
Demographic Questionnaire	1.0	13.12.2012
Self Compassion Scale	1.0	13.12.2012
Recruitment Slip	1.0	13.12.2012
Brief Cope	1.0	13.12.2012
R and D Form	120849/443669/14/450	26.04.2013
SSi Form	120849/443670/6/555/184506/270721	19.04.2013

All research must be managed in accordance with the requirements of the Department of Health's Research Governance Framework (RGF), to ICH-GCP standards (if applicable) and to NHS Trust policies and procedures. Permission is only granted for the activities agreed by the relevant authorities.

All amendments (including changes to the local research team and status of the project) need to be submitted to the REC and the R&D office in accordance with the guidance in IRAS. Any urgent safety measures required to protect research participants against immediate harm can be implemented immediately. You should notify the R&D Office within the same time frame as any other regulatory bodies.

It is your responsibility to keep the R&D Office and Sponsor informed of all Serious Adverse Events. All SAEs must be reported within the timeframes detailed within ICH-GCP statutory instruments and EU directives.

In order to ensure that research is carried out to the highest governance standards, the Trust employs the services of an external monitoring organisation to provide assurance. Your study may be randomly selected for audit at any time, and you must co-operate with the auditors. Action may be taken to suspend Trust approval if the research is not run in accordance with RGF or ICH-GCP standards, or following recommendations from the auditors.

You will be sent an annual progress report which must be completed in order to ensure that the information we hold on our database remains up to date, in line with RGF requirements.

I wish you well with your project. Please do not hesitate to contact me should you need any guidance or assistance.

Yours sincerely



Natassia Embury
R&D Facilitator

Enc: Pi Agreement

Cc: Tom Patterson, Academic Supervisor, Coventry University,
Judith Bond, Coventry and Warwickshire Partnership Trust
Sally Robbins, Coventry and Warwickshire Partnership Trust
Ian Marshall, Sponsor representative, Coventry University

Appendix L

Letter confirming the approval of the study by the Alzheimer's society

Alzheimer's Society
10 Wise Street
Leamington Spa
Warwickshire, CV31 3AP

Tel: 01926 888899
southwarks@alzheimers.org.uk



26th July 2013

Joanna Lloyd,
Trainee Clinical Psychologist,
Clinical Psychology,
James Starley Building,
University of Coventry,
Priory Street,
Coventry.
CV1 5FB

Dear Joanna,

Self-Compassion, Coping Strategies and Burden in Carers of People with Dementia

Thank you for your recent application. I apologise for the delay in responding to you. I am pleased to confirm that I give approval for the project to proceed.

I look forward to seeing the outcome of the research.

Yours sincerely,

Janice Connolly
Locality manager

Appendix M

Letter to potential participants from the Rugby Carers Course

Coventry University
Priory Street, Coventry CV1 5FB
Telephone 024 7688 8328
Fax 024 7688 8702

Programme Director
Doctorate Course in Clinical Psychology
Dr Eve Knight
BSc Clin.Psy.D. CPsychol

THE UNIVERSITY OF
WARWICK



Name

Address

Date

Dear

I am writing to you as you have recently attended a Carer's Course with me at The Railings in Rugby. I would like to take this opportunity to invite you to participate in a research project that is being conducted by me and a student of mine, Jo Lloyd about the experiences of carers of people with dementia. This project is part of Jo's Doctorate in Clinical Psychology. Participation is entirely voluntary; it is up to you to decide if you would like to take part.

We have included an information sheet that explains the study in detail, but briefly, we are interested in the different ways that carers cope in the caregiving role and factors related to this. Participation would involve signing a consent form and filling out 4 questionnaires about you and your caregiving experiences. This will take about half an hour. All of your answers will remain confidential and we have included a stamped addressed envelope for you to return the measures in.

If this study is something you might be interested in taking part in, please read through the information sheet carefully. Take time to think it over and feel free to contact Jo if you have any further questions. If you do decide to participate, please fill in one of the consent forms included with the questionnaires and return it with the completed questionnaires in the envelope provided.

Recruitment letter
Self-Compassion, Coping Strategies and Carer Burden in Carers of People with Dementia
Version 2 28/08/13

Dean of Faculty of Health and Life Sciences
Dr Linda Merriman Mphil PhD DpodM CertEd Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805
Head of Department of Psychology
Professor James Trellian BSc PhD University of Warwick Coventry CV4 7AL Tel 024 7657 3009

www.coventry.ac.uk

Participation in this study is completely voluntary. If you do not wish to participate, you can simply discard the questionnaires or, alternatively, you can return them blank (uncompleted) in the envelope provided.

Thank you for taking the time to read this letter and to consider taking part in the study.

Yours Sincerely

Dr Tom Patterson

Chartered Clinical Psychologist

Appendix N

Participant information sheet (NHS participants)

Coventry University
Priory Street, Coventry CV1 5FB
Telephone 024 7688 8328
Fax 024 7688 8702

Programme Director
Doctorate Course in Clinical Psychology
Dr Eve Knight
BSc Clin.Psy.D. CPsychol

THE UNIVERSITY OF
WARWICK

Coventry University

Coventry and Warwickshire NHS
Partnership Trust

Participant Information Sheet

Exploring Self-compassion, Coping and Carer Burden in Carers of People with Dementia

I would like to invite you to participate in a research project looking into the experiences of carers of people with dementia. Before you decide, we would like you to understand why the research is being done and what it will involve for you.

What is the purpose of the study?

It is understood that caring for a loved one with dementia can at times be both a stressful and a rewarding experience. Previous research has shown that carers often cope well with the stress of their caregiving role. However, sometimes, the stress can lead to carers feeling down or frustrated. We would like to learn more about how carers cope with stress. In particular, we are interested in the coping strategies that are most helpful to them.

In addition to this, we are also interested in learning more about factors that are linked to these helpful coping strategies. Some research has shown that being kind to yourself or *self-compassionate* can affect how people cope with stress. Therefore, we are interested in looking at whether this is also the case for carers of people with dementia.

The information gathered from this study will help us to better understand the experiences of carers and will be used to develop the ways that carers are supported. The study also forms part of the researcher's Doctorate in Clinical Psychology.

Part of Faculty of Health and Life Sciences
Participant Information Sheet - NHS version
Dr Linda Merriam, MPhil, PhD, DPM, CPEd, Coventry University, Priory Street, Coventry, CV1 5FB. Tel 024 7679 5805
Self-Compassion, Coping Strategies and Carer Burden in Carers of People with Dementia
Doctorate in Clinical Psychology
Professor James Tresilian BSc PhD University of Warwick Coventry CV4 7AL Tel 024 7657 3009

www.coventry.ac.uk

Why have I been invited?

You have been invited to participate as you have identified yourself as a carer of someone with dementia, either through attending a post-diagnostic support service or a carer's support group elsewhere. We are hoping that around 80 carers will be involved in this research.

Do I have to take part?

It is up to you to decide to join the study. We will explain the research to you and go through this information sheet. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time. You do not have to give a reason for withdrawing your consent and this decision will not affect the care or support that you receive.

What will I have to do if I take part?

If you decide to take part we will first ask you to sign a consent form stating that you understand the study and wish to take part. There will also be a copy of this for you to keep.

Following this, you will be asked to complete three questionnaires about your individual experiences of caring for someone with dementia. One asks specifically about the coping strategies that you use in response to difficult situations that come up within your caring role. One asks about how you feel about yourself when things are difficult. The third asks more generally about how you feel about your caring role. There will also be a demographic form to fill in about you. This will take about half an hour.

You will be able to fill these questionnaires in with me present so that you can ask any questions. Alternatively, you can take them home and fill them out at a time that suits you. You will be able to return them in the stamped addressed envelope provided or to the professional at the support service where I met you.

What are the possible advantages or benefits of taking part?

We cannot promise that participating in this project will be of any direct benefit for you. However, we hope that the study will help us to better understand the experiences of carers like you. We also hope that it will help us to design services to support carers in their role.

Participant Information Sheet – NHS version
Self-Compassion, Coping Strategies and Carer Burden in Carers of People with Dementia
Version 2 10/06/2013

What are the possible disadvantages of taking part?

The questionnaires are not designed to be distressing or upsetting, however it is possible that some people may become upset. If you feel upset or worried after completing them, you will be able to speak to the researcher if they are present. Alternatively, we would encourage you to speak to your GP about support that may be available, or to call one of the following helplines:

- Dementia Web 24hr Helpline: 0845 1204048
- Alzheimer's Society Helpline: 0300 222 1122 (available between 9:00am – 5:00pm mon – fri and 10:00am – 4:00pm on weekends)

Will my information be kept confidential?

All of your information will be kept confidential. You will only have to put your name on your consent form, not on any of the questionnaires. Your answers will only be linked to your name by the ID number on your consent form and questionnaires. This is so that they can be withdrawn from the study if you want. Your consent form will be stored separately to make sure it stays confidential. I will be the only one to view your questionnaires and they will be stored in a locked filing cabinet.

For auditing or monitoring purposes, data collected during this study may be looked at by individuals from Coventry University, regulatory authorities or the NHS trust where it is relevant to your taking part in this research. By consenting to participate in this study, you also consent to these individuals accessing the anonymised data that you have provided.

What will happen to the information I provide?

The information that you give will be analysed along with the responses from other carers. It will be written up as part of the thesis for a Clinical Psychology Doctorate and for publication in a scientific journal.

What do I do next?

If you do not wish to participate, thank you for your time, you do not need to read any further and you can either discard the questionnaires or return them in the envelope provided.

Participant Information Sheet – NHS version
Self-Compassion, Coping Strategies and Carer Burden in Carers of People with Dementia
Version 2 10/06/2013

If you would like to participate, please read and sign one of the consent forms provided, ensuring that you initial the box next to each statement. The other is for you to keep as it has your participant ID number on.

Please read the instructions on each questionnaire carefully. Try to answer the questions as honestly as you can, to the best of your ability. When you have completed all of the questionnaires, please return them with the completed consent form as soon as possible. You can do this using the stamped addressed envelope provided or you can return them to the professional at the support service where I met you.

Questions, difficulties or concerns

If you have any questions about the study or you would like help with filling out the questionnaires please feel free to contact me by email or leave a message at the telephone number below. I will then be able to call you back to answer any questions or arrange a time to meet with you to discuss the study further.

If you wish to withdraw from the study, you can do so any time until December 2013 when data analysis will have been completed. To withdraw your answers, please return the withdrawal slip included in the pack. Alternatively, contact me by email or leave a message at the telephone number provided below. Please include the ID number from the top of your consent form if you have it and state your wish to withdraw from the study. This will not affect the care or support that you receive.

Finally, we hope to have finished and written up the study by July 2014. After this date, you can also use the contact details below to request a summary of the results.

I would like to thank you for reading this information sheet.

Contact Details

Jo Lloyd

Trainee Clinical Psychologist

Coventry University and the University of Warwick

Lloydj9@uni.coventry.ac.uk

Tel: 02476 888328

For general advice or information on participating in research, or to make a complaint please contact the Patient Advice and Liaison Service (PALS) on 024 7653 6804 or email pals@covwarkpt.nhs.uk.

Appendix O

Participant information sheet (Non-NHS participants)

Coventry University
Priory Street, Coventry CV1 5FB
Telephone 024 7688 8328
Fax 024 7688 8702

Programme Director
Doctorate Course in Clinical Psychology
Dr Eve Knight
BSc Clin.Psy.D. CPsychol

THE UNIVERSITY OF
WARWICK



Participant Information Sheet

Exploring Self-compassion, Coping and Carer Burden in Carers of People with Dementia

I would like to invite you to participate in a research project looking into the experiences of carers of people with dementia. Before you decide, we would like you to understand why the research is being done and what it will involve for you.

What is the purpose of the study?

It is understood that caring for a loved one with dementia can at times be both a stressful and a rewarding experience. Previous research has shown that carers often cope well with the stress of their caregiving role. However, sometimes, the stress can lead to carers feeling down or frustrated. We would like to learn more about how carers cope with stress. In particular, we are interested in the coping strategies that are most helpful to them.

In addition to this, we are also interested in learning more about factors that are linked to these helpful coping strategies. Some research has shown that being kind to yourself or *self-compassionate* can affect how people cope with stress. Therefore, we are interested in looking at whether this is also the case for carers of people with dementia.

The information gathered from this study will help us to better understand the experiences of carers and will be used to develop the ways that carers are supported.

Participant Information Sheet – non NHS version
Self-Compassion, Coping Strategies and Carer Burden in Carers of People with Dementia
Version 1.2 14/03/13

Dean of Faculty of Health and Life Sciences
Dr Linda Merriman Mphil PhD DpodM CertEd Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805
Head of Department of Psychology
Professor James Trellan BSc PhD University of Warwick Coventry CV4 7AL Tel 024 7657 3009

www.coventry.ac.uk

Why have I been invited?

You have been invited to participate as you have identified yourself as a carer of someone with dementia, either through attending a post-diagnostic support service or a carer's support group elsewhere. We are hoping that around 80 carers will be involved in this research.

Do I have to take part?

It is up to you to decide to join the study. We will explain the research to you and go through this information sheet. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time. You do not have to give a reason for withdrawing your consent and this decision will not affect the care or support that you receive.

What will I have to do if I take part?

If you decide to take part we will first ask you to sign a consent form stating that you understand the study and wish to take part. There will also be a copy of this for you to keep.

Following this, you will be asked to complete three questionnaires about your individual experiences of caring for someone with dementia. One asks specifically about the coping strategies that you use in response to difficult situations that come up within your caring role. One asks about how you feel about yourself when things are difficult. The third asks more generally about how you feel about your caring role. There will also be a demographic form to fill in about you. This will take about half an hour.

You will be able to fill these questionnaires in with me present so that you can ask any questions. Alternatively, you can take them home and fill them out at a time that suits you. You will be able to return them in the stamped addressed envelope provided or to the professional at the support service where I met you.

What are the possible advantages or benefits of taking part?

We cannot promise that participating in this project will be of any direct benefit for you. However, we hope that the study will help us to better understand the experiences of carers like you. We also hope that it will help us to design services to support carers in their role.

Participant Information Sheet – non NHS version
Self-Compassion, Coping Strategies and Carer Burden in Carers of People with Dementia
Version 1.2 14/03/13

What are the possible disadvantages of taking part?

The questionnaires are not designed to be distressing or upsetting, however it is possible that some people may become upset. If you feel upset or worried after completing them, you will be able to speak to the researcher if they are present. Alternatively, we would encourage you to speak to your GP about support that may be available, or to call one of the following helplines:

- Dementia Web 24hr Helpline: 0845 1204048
- Alzheimer's Society Helpline: 0300 222 1122 (available between 9:00am – 5:00pm mon – fri and 10:00am – 4:00pm on weekends)

Will my information be kept confidential?

All of your information will be kept confidential. You will only have to put your name on your consent form, not on any of the questionnaires. Your answers will only be linked to your name by the ID number on your consent form and questionnaires. This is so that they can be withdrawn from the study if you want. Your consent form will be stored separately to make sure it stays confidential. I will be the only one to view your questionnaires and they will be stored in a locked filing cabinet.

For auditing or monitoring purposes, data collected during this study may be looked at by individuals from Coventry University, regulatory authorities or the NHS trust where it is relevant to your taking part in this research. By consenting to participate in this study, you also consent to these individuals accessing the anonymised data that you have provided.

What will happen to the information I provide?

The information that you give will be analysed along with the responses from other carers. It will be written up as part of the thesis for a Clinical Psychology Doctorate and for publication in a scientific journal.

What do I do next?

If you do not wish to participate, thank you for your time, you do not need to read any further and you can either discard the questionnaires or return them in the envelope provided.

Participant Information Sheet – non NHS version
Self-Compassion, Coping Strategies and Carer Burden in Carers of People with Dementia
Version 1.2 14/03/13

If you would like to participate, please read and sign **one** of the consent forms provided, ensuring that you **initial** the box next to each statement. The other is for you to keep as it has your participant ID number on.

Please read the instructions on each questionnaire carefully. Try to answer the questions as honestly as you can, to the best of your ability. When you have completed all of the questionnaires, please return them with the completed consent form as soon as possible. You can do this using the stamped addressed envelope provided or you can return them to the professional at the support service where I met you.

Questions, difficulties or concerns

If you have any questions about the study or you would like help with filling out the questionnaires please feel free to contact me by email or leave a message at the telephone number below. I will then be able to call you back to answer any questions or arrange a time to meet with you to discuss the study further.

If you wish to withdraw from the study, you can do so any time until December 2013 when data analysis will have been completed. To withdraw your answers, please return the withdrawal slip included in the pack. Alternatively, contact me by email or leave a message at the telephone number provided below. Please include the ID number from the top of your consent form if you have it and state your wish to withdraw from the study. This will not affect the care or support that you receive.

Finally, we hope to have finished and written up the study by July 2014. After this date, you can also use the contact details below to request a summary of the results.

I would like to thank you for reading this information sheet.

Contact Details

Jo Lloyd

Trainee Clinical Psychologist

Coventry University and the University of Warwick



Lloydj9@uni.coventry.ac.uk

Tel: 02476 888328

For general advice or information on participating in research, or to make a complaint please contact Dr Eve Knight, Course Director of the Clinical Psychology Doctorate at Coventry University on 02476 888328.

Appendix P

Consent Form

<p>Coventry University Priory Street, Coventry CV1 5FB Telephone 024 7688 8328 Fax 024 7688 8702</p> <p>Programme Director Doctorate Course in Clinical Psychology Dr Eve Knight BSc Clin.Psy.D. CPsychol</p>	 
<p>Participant No: 144</p>	
<h3>CONSENT FORM</h3> <h4>Self-Compassion, Coping and Carer Burden in Carers of People with Dementia</h4>	
<p>Please initial all boxes</p>	
<p>I have read and understood the participant information sheet (dated 14/03/2013 version 1.2).</p>	<input type="checkbox"/>
<p>I have had the opportunity to ask questions and these have been answered satisfactorily.</p>	<input type="checkbox"/>
<p>I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.</p>	<input type="checkbox"/>
<p>I understand that data collected during this study may be looked at by individuals from Coventry University, from regulatory authorities and from the NHS trust, where it is relevant to my taking part in this research. I agree for these individual to have access to my records.</p>	<input type="checkbox"/>
<p>I agree to taking part in the above study.</p>	<input type="checkbox"/>
<p>Participant Signature: _____ Print name: _____ Date: _____</p>	
<p>Researcher Signature: _____ Print name: _____ Date: _____</p>	
<p>Consent form Self-Compassion, Coping Strategies and Carer Burden in Carers of People with Dementia Version 1.0 13/12/12</p> <p>Dean of Faculty of Health and Life Sciences Dr Linda Merriman Mphil PhD DpodM CertEd Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805</p> <p>Head of Department of Psychology Professor James Tresilian BSc PhD University of Warwick Coventry CV4 7AL Tel 024 7657 3009</p> <p>www.coventry.ac.uk</p>	

Appendix Q

Recruitment Slip

Coventry University
Priory Street, Coventry CV1 5FB
Telephone 024 7688 8328
Fax 024 7688 8702

Programme Director
Doctorate Course in Clinical Psychology
Dr Eve Knight
BSc Clin.Psy.D. CPsychol

THE UNIVERSITY OF
WARWICK



Can You Help?

Do you know any other carers of people with dementia who might also like to be involved in this study?

If so, please pass on this slip and ask them to contact the researcher, Jo Lloyd for more information using the details provided.

Thank you for your help.

Jo Lloyd
Trainee Clinical Psychologist
Coventry University and the University of Warwick
Email: Lloydj9@uni.coventry.ac.uk
Tel: 02476 888328

Recruitment Slip
Self-Compassion, Coping Strategies and Carer Burden in Carers of People with Dementia
Version 1.0 13/12/12

Dean of Faculty of Health and Life Sciences
Dr Linda Merriman Mphil PhD DpodM CertEd Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805
Head of Department of Psychology
Professor James Tresilian BSc PhD University of Warwick Coventry CV4 7AL Tel 024 7657 3009

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Appendix R

Debrief Sheet

Coventry University
Priory Street, Coventry CV1 5FB
Telephone 024 7688 8328
Fax 024 7688 8702

Programme Director
Doctorate Course in Clinical Psychology
Dr Eve Knight
BSc.Clin.Psy.D. CPsychol

**THE UNIVERSITY OF
WARWICK**

**Coventry
University**

Participant Debrief Sheet

Exploring Self-compassion, Coping and Carer Burden in Carers of People with Dementia

Thank you for taking part in this study, your answers are very helpful to us.

This aim of this research is to explore the relationship between self-compassion, coping strategies and the amount of stress or burden experienced by carers of people with dementia.

It is understood that caring for a friend or relative with dementia can at times be a stressful experience, which can affect carer's physical and mental health. Therefore it is important for us to find ways of helping carers to cope with the stress they face. Research shows that carers use many different strategies to manage stress, and that some are more helpful than others. This project is looking at 2 main types:

- *Emotion focused strategies* try to change how we think and feel about the stressful situation, such as trying to see the positive side.
- *Dysfunctional strategies* such as avoiding the stressful situation, feel helpful in the short term, but may not resolve things long term.

Research suggests that carers of people with dementia report less burden when they use more emotion-focused strategies and fewer dysfunctional strategies. I will use the answers to some of the questionnaires to confirm if this is the case.

Other research suggests that people who are kind to themselves or *self-compassionate* cope better with stress. It seems that people who are more self-compassionate use more emotion-focused coping strategies and fewer dysfunctional strategies. I will use the answers to the other questionnaires to see if this is also for carers of people with dementia.

Participant Debrief Sheet
Self-Compassion, Coping Strategies and Carer Burden in Carers of People with Dementia
Version 1.0 14/03/13

Dean of Faculty of Health and Life Sciences
Dr Linda Meriman: Mphil PhD DpodM CertEd Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805

Head of Department of Psychology
Professor James Tresilian BSc PhD University of Warwick Coventry CV4 7AL Tel 024 7667 3009

www.coventry.ac.uk

This research is important as it could help us to identify alternative ways of supporting carers to cope with stress through helping them to be more self-compassionate. In addition, it also helps us to understand more about the factors that are important in the caregiving experience.

We understand that answering questions about stress and your caregiving role can bring up difficult feelings for some people. If you would like to talk to somebody about your thoughts or feelings, please contact one of the following:

- Dementia Web 24hr Helpline: 0845 1204048
- Alzheimer's Society Helpline: 0300 222 1122 (available between 9:00am – 5:00pm mon – fri and 10:00am – 4:00pm on weekends)
- Your GP will also be able to advise you on other support available in your area.

If you have any complaints, concerns or questions about this research, please contact:

Jo Lloyd

Trainee Clinical Psychologist

Coventry University and the University of Warwick

Lloydj9@uni.coventry.ac.uk

Tel: 02476 888328

If you are interested in this area of research, you may like to read the following references:

Cooper, C., Katona, C., Orrell, M. and Livingston, G. (2008). Coping strategies, anxiety and depression in caregivers of people with Alzheimer's disease. *International Journal of Geriatric Psychiatry*, 23, 929–936.

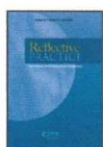
Neff, K. D. (2004). Self-compassion and psychological wellbeing. *Constructivism in the Human Sciences*, 9, 27 – 37.

Thank you again for your participation.

Participant Debrief Sheet
Self-Compassion, Coping Strategies and Carer Burden in Carers of People with Dementia
Version 1.0 14/03/13

Appendix S

Author instructions for *Reflective Practice*



Reflective Practice

International and Multidisciplinary Perspectives

Instructions for authors

SCHOLARONE MANUSCRIPTS

This journal uses ScholarOne Manuscripts (previously Manuscript Central) to peer review manuscript submissions. Please read the [guide for ScholarOne authors](#) before making a submission. Complete guidelines for preparing and submitting your manuscript to this journal are provided below.

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To ensure anonymous peer review, all identifying information should be removed and your article should be uploaded as "Main Document". A title page, including author information, can be uploaded separately.

Writers need to bear in mind that they are addressing an international and multidisciplinary audience. Non-discriminatory language should be used, key terms need to be clearly defined and portraits of the context in which the work is situated needs to be given where appropriate.

Word Length

Reflective Practice publishes articles of up to 6,000 words (inclusive of references) or equivalent in length. Additionally, the journal welcomes shorter pieces on: recent initiatives; reports of work in progress; proposals for collaborative research; theoretical positions; knowledge reported in poetic, diagrammatic and narrative form, illuminated by line drawings and photography; provocative problem and question posing thought pieces; reflective dialogues; creative reflective conversations.

Tables, figures and other illustrative material needs to be completely understandable and independent of the text. Tables need to be typed and submitted on separate sheets and not included as part of the text. The captions to all tables, figures and other illustrative material needs to be gathered together and typed on a separate sheet. Please supply clear camera-ready copies of artwork and in a finished form suitable for reproduction. Figures will not normally be redrawn by the publisher. The negatives of any photographs to be used in the paper will need to be sent to the Editor. Tables and all other illustrations should be numbered by Arabic

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Description of the Journal's [article style](#), [Quick guide](#)

Description of the Journal's [reference style](#)

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This journal requires a short paragraph of bibliographical details for all contributors.

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If you have any questions about references or formatting your article, please contact authorqueries@tandf.co.uk (please mention the journal title in your email).

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